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## **Ethnicity, Psychosis and Co-Morbid Substance Use Disorders in the U.K.**

Mearhart, Jozella Selina Sophia

*Awarding institution:*  
King's College London

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# **Ethnicity, Psychosis and Co-Morbid Substance Use Disorders in the U.K.**

**Jozella Mearhart BSc. (Hons.) M.A. Economics**

**Thesis submitted to Kings College London  
for the degree of Doctor of Philosophy in  
Psychological Medicine & Psychiatry**

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# **ABSTRACT**

## **BACKGROUND**

The relationship between psychotic disorders and substance use is well established but complex. High rates of psychosis and greater risk of negative outcomes have been found in Black Caribbean and Black African groups. In addition research within the general population has shown important ethnic differences in patterns of substance use disorders (SUD). An under researched issue is the impact of SUDs on treatment and outcomes for people suffering from psychosis and whether this impact differs by ethnic group.

## **METHOD**

This PhD study aimed to investigate the prevalence, correlates and experiences of comorbid SUDs in patients with an 8-12 year history of psychosis with special attention to Black African and Black Caribbean groups. The study comprised two phases. The first phase utilised data from the AESOP-10 follow-up study of 325 epidemiologically based White British, Black Caribbean and Black African individuals who originally presented to psychiatric services in London and Nottingham between 1997 and 2000 with a psychotic disorder. The second phase was a qualitative study that purposefully selected a sub-sample of patients from the AESOP London cohort.

## **AIMS AND HYPOTHESES**

It was hypothesised that there would be higher rates of SUDs in Black Caribbean and lower rates in Black African ethnic groups compared to White groups and that irrespective of ethnicity comorbidity will be associated various negative factors. The second phase aimed to describe the experiences of mental illness, SUDs and treatment experiences in all ethnic groups.

## RESULTS

The quantitative study found that Black African patients had a significantly lower prevalence of SUDs than White patients (Comorbid DUD: OR 0.090, CI 0.025-0.327,  $p=0.000$ ; Comorbid AUD: OR 0.066, CI 0.013-0.322,  $p=0.001$ ). Black Caribbean patients with drug use disorders and White British patients with alcohol use disorders were more likely to have negative outcomes however many these findings failed to reach statistical significance.

Findings from the qualitative study highlighted the use of numerous devices and mechanism in account giving. Several thematic constructions were uncovered including lay models of illness aetiology, perceptions of a causal relationship between illness experiences and substance use, perceptions of a relationship between cannabis and paranoia, perceptions of cannabis use as non-problematic and the importance of the role health services (particularly talking based therapies), family and mastery play in the treatment and recovery process.

## CONCLUSIONS

Mixed method design involving large longitudinal epidemiological and qualitative studies are an appropriate way of investigating the relationship between psychosis and substance use disorders. Patients with comorbid SUDs may be more likely to have subsequent relapses and hospital admissions over the course of their illness, however the likelihood of this may differ for different ethnic groups and type of substances used. Talking based treatments which focus on lay models of aetiology, mastery of symptoms and cannabis use and involve the patients larger social networks are likely to be of benefit to this population. Further epidemiological and qualitative research into the changing patterns of substance use over a time are necessary.



## **STATEMENT OF AUTHORSHIP**

The idea to investigate the ethnic differences in comorbid psychosis and substance use disorders was developed from my long standing interest in the dual diagnosis and discussions with my first (Dr. Craig Morgan) and second (at that time Dr. Paul Fearon) PhD supervisors. The review of the literature in Chapters 2 and 3 as well as the systematic review of ethnicity and comorbidity in Chapter 4 was my own work.

Data for the baseline Aetiology and Ethnicity of Schizophrenia and Other Psychoses (AESOP) study was collected between 1997 and 2000, the method for this study is outlined in Chapter 6. This data was collected by a team of researchers in South East London and Nottingham headed by Professor Robin Murray and Professor Peter Jones respectively. I was not involved in the collection of this data. During my PhD I worked as part of a team of researchers in London headed by Dr. Paul Fearon, Dr. Paola Dazzan and Dr. Craig Morgan to trace and re-contact participants in the original London cohort (AESOP-10). The method for this is presented in Chapter 6. As part of the team of researchers I was jointly responsible for the interviewing and examination of clinical case notes for London participants using the main outcome schedules (including the SCAN diagnostic interview and the WHO Life Chart). I was involved in consensus diagnosis meetings in London attended by the principle investigators and other members of the research team. This data was utilised for Phase One of the PhD study and is summarised in Chapter 8.

The design for Phase Two of the PhD was developed after discussions with my first supervisor Dr. Craig Morgan. I developed a detailed proposal for the study, along with additional study documents (participant information sheet, participant consent form and interview topic guide) for submission to NRES Bexley and Greenwich Research

Ethics Committee (REC Reference 08/H0809/8). On 9<sup>th</sup> May 2008 the Ethics Committee awarded me a favourable ethical opinion for the Phase Two Qualitative study (see appendix 1). Participants for Phase Two were identified through the AESOP-10 study by me and other members of the research team (see Chapter 6). I was solely responsible for all data collection (qualitative interviews) and data analyses for the qualitative study. All data analyses and summaries of results for both phases of this PhD (Chapters 8 and 9) were my own work. The PhD thesis presented here was written and edited after comments from my first (Dr. Craig Morgan) and second (Dr. Stephani Hatch) supervisors by me.

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## **CHAPTER 1: INTRODUCTION**

There is a well-established association between the presence of mental health problems and drug and alcohol use disorders (Mueser et al., 1992; Strathdee et al., 2002; Weaver et al., 2002; Farrell et al. 2004), but the aetiological relationship between the two is complex and little is understood despite recent advances in the understanding of how certain substances can increase risk of mental disorder, notably psychotic illness (Mueser et al., 1992; Strawkowski, et al., 1993; Cantor-Graae et al., 2001)

High rates of psychosis have been well documented in Black Caribbean and Black African groups (Sharpley et al., 2001) and there are numerous studies showing these groups are at greater risk of compulsory admission to hospital (Bhui et al., 2003; Morgan et al., 2004; Morgan et al., 2005), and more likely to be treated in secure and forensic settings (Bhui et al., 2003; Morgan et al., 2004). However, reasons for this remain unclear (Morgan et al., 2004).

An under-researched issue is the impact of substance use disorders on treatment and outcomes for people suffering from psychosis. This is in spite of evidence suggesting that comorbidity is associated with increased psychiatric admissions and poor outcomes (including worsening psychiatric symptoms, increased use of institutional services, poor medication adherence and contact with the criminal justice system) in both mental health and drug abuse treatment services (Hunt et al. , 2002).

Since the 1980s there has also been evidence indicating that most of the serious drug-related problems are in areas of high unemployment and social deprivation (Haw, 1985; Pearson, 1987a & 1987b; Peck &

Plant, 1986), where the majority of young Black and minority ethnic groups live.

Studies investigating the epidemiological patterns of substance abuse have found important differences according to ethnicity. Substance use, abuse or dependence among Black Caribbeans often centres on crack-cocaine use and cannabis use, although low levels of substance use have been found in Black African populations (Aust, 2003).

## **1.1 RATIONALE FOR THE INVESTIGATION AND STRUCTURE OF THE THESIS**

Given the potential service implications, this is an issue that merits much more research. A recent study has shown that Black British groups being treated for psychosis were significantly more likely to be diagnosed as having comorbid cannabis use and Black African groups were significantly more likely to be diagnosed with abusing stimulants and opiates than White groups (Afuwape et al., 2006). Despite finding ethnic differences in the prevalence of comorbidity, this study was a cross-sectional community-based study which used case manager ratings of substance abuse/dependence in patients with established illness.

There is a need for robust longitudinal population-based studies, which can explore the various interactions ethnicity may have with comorbid diagnosis. This study will estimate the prevalence of comorbid psychosis and substance abuse/dependence in different ethnic groups giving special attention to Black African and Black Caribbean populations. Using a mixed method design, it will also explore in detail the relationship between comorbid diagnosis and various clinical and psychosocial outcomes as well as service provision and the perceived quality of care in the 10 years following first contact with services.

### **1.1.1 Aims, hypotheses and research questions**

The PhD study is nested within the larger MRC funded AESOP-10 (Aetiology and Ethnicity in Schizophrenia and Other Psychoses) follow-up study which looked at the course and outcome of psychosis in an ethnically-diverse cohort of psychiatric patients being followed-up 8-12 years after their first presentation to services.

The overall objectives of the PhD study were:

- 1) To make a theoretical and methodological contribution to the understanding of the relationship between comorbidity of psychosis and substance use disorder and ethnicity.
- 2) To estimate the prevalence and correlates of comorbidity of psychosis and substance use disorder in different ethnic groups.
- 3) To describe service responses to, and the perceived quality of care of patients with, comorbid diagnoses from different ethnic populations, giving special attention to Black Caribbean and Black African groups.

To achieve these objectives two hypotheses were tested in the first quantitative phase of the study. This study hypothesises that:

- 1) The prevalence of comorbid substance use disorders in individuals with an 8-12 year history of psychosis will differ according to ethnic group. More specifically, rates of comorbidity will be higher in Black Caribbean, and lower in Black African, patients than White patients.
- 2) In all ethnic groups, comorbid substance use disorder will be associated with:
  - a) more frequent relapses and



b) more compulsory admissions  
independent of potential confounders, including age, gender,  
diagnosis and study centre.

Although the study hypothesised that poorer outcomes will be evident in patients from all three ethnic groups with comorbidity compared to those that only have a psychotic illness, it is likely that a greater prevalence of comorbid psychosis and substance use disorders in the Black Caribbean group will show a higher risk for poor outcomes than in White or Black African groups over the 8-12 year follow-up period.

The second, qualitative phase of the study, which purposefully selected a sub-sample of patients from the AESOP-10 cohort, investigated the following research questions:

- 1) How do individuals with comorbidity of psychosis and substance use disorders construct their experiences of 'psychosis' and drug and alcohol use 8-12 years after their first episode?
- 2) How do individuals with comorbidity of psychosis and substance use disorders construct their experiences of mental health and substance abuse treatment services?
- 3) What is the perceived role (if any) of family, friends and other social support networks in the treatment process for 'psychosis' and substance use disorder?

In other words the second arm of the study aimed to both describe if and how the problem of comorbidity differs for ethnic minorities in psychotic populations and to identify conceptualisations of illness and substance use. The study also aimed to explore the impact comorbidity might have on attitudes towards the perceived usefulness of treatment approaches (namely hospitalisation and community treatment) and the role family, friends and alternative forms of support play in the recovery process.

It should be noted that although the AESOP-10 study included patients from all ethnic backgrounds, the first half of the PhD study focuses on three broad ethnic groups: White, Black Caribbean and Black African. This is because firstly the numbers in other ethnic categories were too small to be compared separately and were too diverse to be combined. Secondly, previous research has tended to focus on crude categorisations and comparisons of ethnic differences and so a basis for comparison needed to be established in this study.

### **1.1.2 Thesis outline**

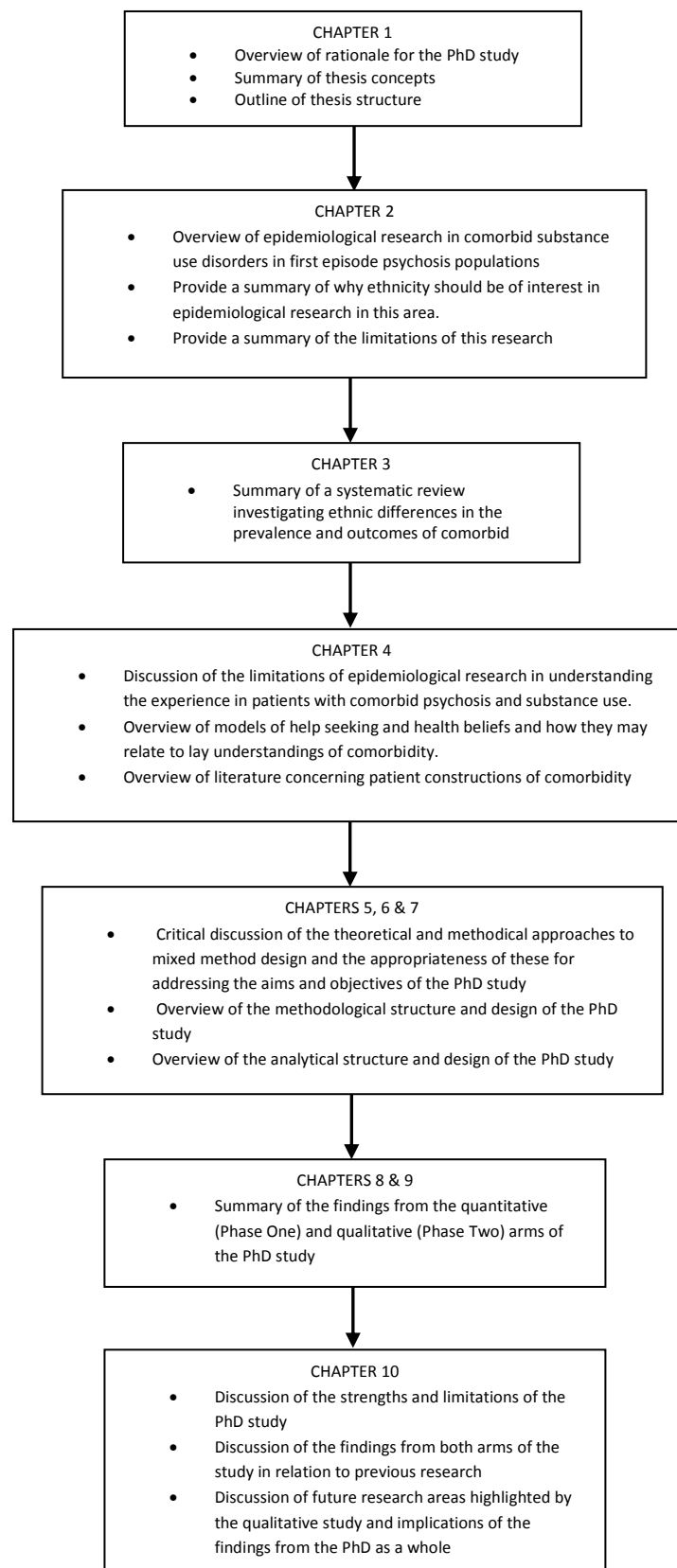
The thesis falls into four main sections. Figure 1 summarises the aims and objectives of each chapter. The first part forms the background to the PhD study and includes a review of epidemiological and anthropological literature in the areas of comorbidity, service utilisation of patients with dual diagnosis and constructions of the lived experience of comorbidity.

Chapter 2 builds on the concepts discussed in section 1.2 and details the characteristics and correlates of first-episode psychotic patients with comorbid substance use disorders, their outcomes and the basis for consideration of the role ethnicity may play in prevalence and outcome.

Chapter 3 follows on from this by presenting the findings from a systematic review of current literature on ethnicity and comorbidity with particular attention given to ethnic differences in prevalence and ethnicity as a risk factor for comorbid diagnosis.

Chapter 4 discusses the limitations of epidemiological literature in understanding the construction of experience in patients with comorbid psychosis and substance use. It discusses models of health beliefs and how they may relate to lay understandings of comorbidity.

**Figure 1: Summary of Thesis Chapters**



The second part of the thesis gives an overview of the methodological aspects of the PhD study. Chapter 5 discusses the theoretical considerations for conducting mixed-method health services research and gives an overview of the ontological and epistemological framework within which the PhD study is situated. Chapter 6 then describes the method that was used to address the hypotheses and research questions. It gives an overview of the AESOP-10 study which the quantitative phase of the PhD was situated within as well as detailing the selection, sampling, recruitment and interviewing of a sub-sample of AESOP-10 patients for the second qualitative phase of the study. Chapter 7 moves onto the analytical structure for the epidemiological first phase as well as the qualitative second phase of the PhD study.

The third section of this thesis provides a detailed summary of the findings of both phases of the study. Chapter 8 summarises the quantitative findings and Chapter 9 summarises the qualitative findings. The thesis' final part draws on the background literature, methodological considerations and findings for both arms of the study. Chapter 10 is a full discussion of the findings of both arms in relation to what we already know and predicted and then highlights the potential clinical applications of these findings as well as the limitations of the study. This Chapter provides a summary of the conclusions that can be made from the PhD study.

## **1.2 DEFINING CONCEPTS**

### **1.2.1 Psychosis**

Psychosis is an umbrella construct which includes a range of disorders (Ross, 2005) which are characterised by the primary presence

of what psychiatry terms positive symptoms such as hallucinations and delusions.

In current classification systems (World Health Organisation (WHO) International Statistical Classification of Diseases and Related Health Problems (ICD-10) and American Psychological Association Diagnostic and Statistical Manual of Mental Disorders, 4th Edition) the following diagnoses are grouped under the umbrella of psychosis: schizophrenia, schizotypal disorder, schizophreniform, persistent delusional disorders, acute and transient psychotic disorders, induced delusional disorder, schizoaffective disorders, other nonorganic psychotic disorders, shared psychotic disorder, brief psychotic disorder and unspecified nonorganic psychosis.

Conceptualisation of psychosis in this thesis was largely determined by the nature of the sample and the measures completed upon them. In other words the thesis is concerned with individuals who presented to psychiatric services for the first time with evidence of psychotic symptoms regardless of their diagnosis between 1997 and 2000. Patients were recruited according to the Screening Schedule for Psychosis (Jablensky et al., 1992) (for overview of AESOP study methods see section 6.3) and had to fulfil the criteria for either A or B below with no evidence of an organic cause.

**A.** At least *one* of the following:

- Hallucinations or pseudo-hallucinations in any modality
- Delusions
- Marked thought and speech disorder (e.g. incoherence, irrelevance, thought blocking, neologisms incomprehensibility of speech etc.) other than simple retardation or acceleration
- Marked psychomotor disorder (e.g. negativism, mutism or stupor, catatonic excitement, constrained attitudes or unnatural postures maintained for long periods etc.) other than simple retardation or acceleration

- Emergence or marked exacerbation of bizarre and grossly inappropriate behaviour (e.g. talking or giggling to self, acts incomprehensible to others, loss of social constraints etc.).

**B.** At least two of the following:

- Marked reduction or loss of interests, initiative and drive, leading to serious deterioration of the performance of usual activities and tasks
- Emergence or marked exacerbation of social withdrawal (active avoidance of communication with other people)
- Severe excitement, purposeless destructiveness or aggression
- Episodic or persistent states of overwhelming fear or severe anxiety
- Gross and persistent self-neglect

### **1.2.2 Comorbidity and Dual Diagnosis**

According to current classification systems (ICD-10 and DSM-IV TR) in psychology and psychiatry, mental disorders are diagnosed according to operationalised diagnostic criteria and the diagnosis of one disorder does not necessarily preclude the diagnosis of another. Comorbidity is defined in general terms as the co-occurrence of two or more mental disorders. More specifically within psychiatry, comorbidity is most commonly used to describe the overlap of two or more psychiatric disorders (Boyd et al., 1984).

Comorbidity between substance use disorders and other mental disorders has gained increasing prominence in psychiatry and psychology within the past few decades and is sometimes referred to as 'dual diagnosis' with both terms being used interchangeably (Wittchen et al., 1996). In practice, comorbidity is specifically restricted to include severe

mental illness (SMI) – psychosis, schizophrenia, bipolar affective illness and substance use disorder (Todd et al., 2004).

The chronology of disorders in comorbid diagnosis is important in determining aetiology (which I touch on in Chapter 4) as comorbidity can occur when a substance use disorder is primary and dominant, but underlined by at least one other psychiatric disorder or the mental disturbance may be considered the primary condition (Franey & Quirk, 1996).

For a comorbid diagnosis DSM-IV and DSM-IV TR make clear distinctions between an independent psychotic disorder (e.g. bipolar disorder, schizophrenia etc.) and substance-induced syndromes (e.g. delirium, dementias etc.). Most substance-induced psychotic symptoms are considered to be short-lived and to resolve after a period of sustained abstinence along with other symptoms of substance intoxication and withdrawal (Rounsaville, 2007). This however is likely to be challenged by mounting evidence that marijuana use may be a contributing cause of schizophrenia (Arseneault et al., 2004).

Definitions of comorbidity have sometimes been loosely applied in epidemiological studies to include co-occurring substance use (Barnes et al., 2006) and have focused on current (Cantor-Graae et al., 2001) as well as lifetime diagnoses (Kavanagh et al., 2004). However, this study uses the tight definition of co-occurring diagnoses of a psychotic disorder and lifetime substance abuse or dependence according to DSM-IV.

#### Drugs:

- Substance abuse (Maladaptive use leading to any of the following: (1) failure to fulfil major role obligations due to substance; (2) substance leading to, or exacerbating, social or interpersonal problems; (3) recurrent abuse when physically hazardous (e.g. driving) or substance-related legal problems).
- Substance dependence (Maladaptive use leading to 3 of the following: (1) increased tolerance; (2) symptoms of withdrawal;

(3) substance taken in larger amounts over a longer period than originally intended ;(4) persistent desire, or unsuccessful attempts, to cut down; (5) much time spent in activities to obtain the substance or recovering from effects; (6) impairment of social, occupational or recreational activities due to substance; (7) persistent use despite harmful physical or psychological effects.

#### Alcohol:

- Alcohol abuse (Maladaptive use leading to any of the following: (1) failure to fulfil major role obligations due to alcohol; (2) substance leading to, or exacerbating, social or interpersonal problems; (3) recurrent abuse when physically hazardous (e.g. driving) or alcohol-related legal problems).
- Alcohol dependence (Maladaptive use leading to 3 of the following: (1) increased tolerance; (2) symptoms of withdrawal; (3) alcohol taken in larger amounts over a longer period than originally intended; (4) persistent desire, or unsuccessful attempts, to cut down; (5) much time spent drinking the substance or recovering from effects; (6) impairment of social, occupational or recreational activities due to alcohol; (7) persistent use despite harmful physical or psychological effects of alcohol.

The term substance use disorder is used throughout the thesis but it should be noted that this includes substance abuse and dependence.

Patients characterised as having a diagnosis of comorbidity will have been diagnosed with a psychotic disorder around their initial episode of illness and will have met criteria for a substance use disorder (substance abuse or dependence) at some point during their lifetime.



### **1.2.3 Race, ethnicity and culture**

Race, culture and ethnicity have multiple and sometimes ambiguous meanings, which often overlap with political concepts of nationality and immigration status (Singh, 1997). Fernando, (1991) has argued that race is socially perceived as permanent and genetically determined. Singh (1997) summarises ethnicity and culture in the following ways:

- An ethnic group refers to a group of people that share language, customs and a recent common ancestry and definitions of ethnicity encompass biological and non-biological differences between groups (for example physical appearance, self-identification, values and attitudes, language, behaviour and knowledge of that ethnic groups history).
- Culture involves the shared characteristics of a society for example traditions, language, social roles. These characteristics are transmitted across generations by non-biological means.

The main differences between race, ethnicity and culture are that race is generally considered unchangeable while culture is considered changeable and ethnicity is considered partially changeable (Fernando, 1991).

Traditionally the term race was used in social and scientific arenas (Huxley & Haddon, 1935). However, after the Second World War arguments that social rather than biological inequalities were responsible for differences in populations led to the term ethnicity replacing race in socio-political discourse and scientific and medical research (Singh, 1997). This thesis is concerned with the concept of ethnicity and its relationship to both psychotic and substance use disorders.

Although ethnicity has been widely studied in sociological and anthropological fields since the late 1960s, ethnicity, ethnic groupings and ethnic diversity remain highly contested concepts (Brown & Langer, 2010). There is no universally accepted definition of ethnicity but it is

generally conceptualised as a sense of group belonging, based on common ideas, history, culture, language, experience and values (e.g. Glazer & Moynihan, 1975; Anderson, 1983; Horowitz, 1985; Bates, 2006).

Singh argues that in Britain, Caucasian (now associated with the term White), Asian and Afro Caribbean are considered the main ethnic groups and that all of these groups are heterogeneous and socially perceived (Singh, 1997). In addition self-assigned ethnicity (where the participant assigns themselves to an ethnic category that most represents their identity) has become popular in social science research because it reduces observer bias. However, research that offers participants a limited range of ethnic categories (albeit popular ones), as Singh notes may force respondents to 'pigeonhole themselves in artificially chosen constructs.' (Singh, 1997, p. 306).

Despite epidemiological studies using self-defined ethnicity variables to uncover patterns of aetiology and outcome by reducing it to mutually exclusive ethnic categories, Brown and Langer argue that as long as the interpretation of results acknowledges the limitations of this kind of categorisation, quantitative analysis can provide a useful and systematic form of comparison (Brown & Langer, 2010).

In both phases of the PhD study information relating to ethnicity was based on data collected from the AESOP baseline study. Ethnicity for all people who took part in this study, was defined according to the self-report criteria used in 2001 UK census. The criteria employed by the UK Office of National Statistics (ONS) census in 2001 included 16 categories:

- a) White British;
- b) White Irish;
- c) Other White;
- d) Mixed: White and Black Caribbean;
- e) Mixed: White and Black African;
- f) Mixed: White and Asian;
- g) Other Mixed;

- h) Indian;
- i) Pakistani;
- j) Bangladeshi;
- k) Other Asian;
- l) Black Caribbean;
- m) Black African;
- n) Black Other;
- o) Chinese; and
- p) Other.

The qualitative phase of the PhD study included a description of respondents' self-ascribed ethnicity without using predefined ethnic groupings.

### **1.3 SUMMARY**

The following PhD study aims to make a theoretical and methodological contribution to the understanding of the relationship between comorbidity of psychosis and substance use disorder and ethnicity. It also aims through a mixed design to estimate the prevalence and correlates of comorbidity in different ethnic groups as well as uncover patient perceptions of psychotic illness, substance use and service responses within different ethnic populations.

The chapters that follow provide essential background literature and a detailed overview of the PhD study's theoretical and methodological structure. This is followed by a summary of the findings from both phases of the study and finally a discussion of these findings in relation to the study's limitations and previous epidemiological and qualitative research.

## Chapter Summary 1.

### Chapter Summary

#### Aims of the Chapter:

To provide a brief overview of the rationale for the PhD study. To summarise the structure of the PhD study thesis and define concepts within it.

#### Key Points:

- There is a need for robust longitudinal population-based studies, which can explore the various interactions ethnicity may have with comorbid diagnosis
- Psychosis is an umbrella construct which includes a range of disorders and was largely defined by the PhD study sample.
- Comorbidity in this study is defined as: the co-occurring diagnoses of a psychotic disorder and lifetime substance abuse or dependence according to DSM-IV
- Definitions of ethnicity in this study were self-reported and based on criteria used in 2001 UK census

## **CHAPTER 2: EPIDEMIOLOGY OF COMORBID SUBSTANCE USE DISORDERS IN FIRST EPISODE PSYCHOSIS AND FOLLOW-UP**

### **2.1 INTRODUCTION**

The aim of this chapter (as well as the proceeding two chapters) is to build on the rationale for the PhD study by providing an overview of some of the most prominent epidemiological research in the area of comorbid substance use disorders in first episode psychosis populations. The chapter begins with outlining study estimates of prevalence and risk for comorbidity and moves onto summarising the relationship between comorbidity and outcome. Turning next to the aims and objectives of the PhD study the chapter addresses the question why ethnicity should be of interest in epidemiological research in this area. Finally a summary of the limitations of this research is given.

### **2.2 COMORBID SUBSTANCE USE DISORDERS IN FEP**

#### **2.2.1 Prevalence, correlates and risk**

Co-occurring substance use is common among people with psychotic disorders and has important implications for the course and treatment of psychosis. Several epidemiological studies have examined the prevalence and correlates of substance use disorders in people in their first episode of psychosis (FEP). Typically, higher rates of substance use disorders have been reported in FEP patients when compared to the general population. Findings however vary significantly between studies and countries.

The highest rates of substance use disorders have been reported in the USA, although ranges have been found from 10% to as high as 70% (Mueser et al., 1990). Canada on the other hand has prevalences between 35% and 45%, (Archie et al., 2007; Van Mastrigt S., Addington J. & Addington D., 2004).

Epidemiological research into the prevalence of comorbidity in Australia have reported prevalences of substance use disorders of roughly 40%, (Kavanagh et al., 2004; Lambert et al., 2005), while closer to home prevalences reported in Europe range from 14% to 23%, (Cantwell et al., 1999; Hambrecht & Hafner , 2000; Sorbara et al., 2003; Larsen et al., 2006).

Some of the lowest rates found were from Singapore (6%) (Verma et al., 2002).

In the UK specifically a systematic review of rates of comorbid substance misuse and psychosis in UK studies between 1986 and 2007 by Carra and Johnson (2009) showed ranges of prevalence between 12% (Virgo et al., 2001) and 75% (Gaite et al., 2002) across various treatment settings. For example, in inpatient settings prevalences ranged from 20% (Sanders et al., 1993) to 50% (Phillips & Johnson, 2003).

Differences in prevalence may have been due to the way substance misuse data was collected. For example, in CMHT caseloads, rates of alcohol and drug misuse taken from staff reports estimated around 12% and 13% respectively (Miles et al., 2003; Virgo, Bennett G., Higgins D., Bennett L. & Thomas P., 2001; Weaver et al., 2001), whereas diagnostic interviews ranged from 16% to 27% (Barnes et al., 2006; Cantwell et al., 1999) and consensus rating methods ranged between 20% and 26% (Menezes et al., 1996; Weaver et al., 2003; Wright et al., 2000).

While it is clear that prevalence of comorbidity is high in psychotic populations the observed variation in prevalence across countries and studies could be due to methodological inconsistencies between studies,

but also to cultural and environmental differences between countries, especially in substance availability (Mazzoncini et al., 2009).

Substance use has also been found to be a risk factor for the onset of schizophrenia (Smith et al., 2004; Semple et al., 2005) and the use of cannabis in adolescence has been reported to increase the risk of developing symptoms of schizophrenia in adulthood (Tsapakis et al., 2003). Cannabis use specifically has been found to increase the risk of both the incidence of psychosis in the general population and a poor prognosis for those with an established vulnerability to psychotic disorder (Van Os et al., 2002).

In a Cambridgeshire study age of first use of cannabis, cocaine, ecstasy and amphetamine was found to be significantly associated with age at first psychotic symptom (Barnett et al., 2007). Prevalence of the types of substances used by people with psychosis also vary across studies, however cannabis is consistently reported as the most frequently used illicit substance (Cantwell et al., 1999; Regier et al., 1990). Evidence suggests an increased risk of cannabis exposure prior to onset of psychosis (Moore et al., 2007) though the frequency of poly-drug use can make it difficult to disentangle the effects of each individual substance (Addington J. & Addington D., 2007).

In an Australian study of first admission for psychosis Sara, Burgess, Malhi, Whiteford and Hall (2013) found that diagnoses of drug-induced psychoses were more strongly associated with stimulants than with cannabis. They also found that, compared to patients with cannabis diagnoses alone, those with both cannabis and stimulant disorders were older, more likely to have a diagnosis of drug-induced psychosis and more likely to have comorbid alcohol disorders (Sara et al. , 2013).

Comorbid substance use has also been associated with unemployment, less desirable living conditions (Drake, Osher & Wallach, 1991), a lower educational level (Dixon L., 1999), more family problems and single relationship status (Dixon, McNary & Lehman, 1995).

However, reliable clinical correlates of substance use in patients with psychosis have yet to be identified (Mazzoncini et al., 2009).

Some studies have also reported that substance misusers are more likely to have an acute mode of illness onset, a shorter duration of untreated psychosis (DUP) (Morgan et al., 2006) and to be admitted compulsorily at first contact with psychiatric services (Wade D., Harrigan S., McGorry P. D., Burgess P. M. & Whelan G., 2007; Dean et al., 2007).

It should be noted, however, that a major limitation of previous studies in this area is their small sample sizes and inconsistent categorisation and measurement of comorbidity (Mazzoncini et al., 2009).

## **2.3 COMORBIDITY AND FOLLOW-UP IN FEP**

There is a small collection of epidemiological research which looks at the clinical, social and service use outcomes of patients with comorbid substance use disorders and FEP. Most follow-up studies have tended to range from twelve months to five years after the initial episode of illness and have focused on reduction of psychotic symptoms, reduction of substance use, global function and likelihood of readmission.

### **2.3.1 The relationship between comorbidity and clinical/social outcomes in psychosis**

Studies have revealed similar motives for substance use in psychotic populations as in the general population with “coping” and “enhancement” motives found to lead to substance use problems and dependence (Spencer, Castle & Mitchie, 2002).



Comorbidity has typically been associated with more severe psychotic symptomatology (Margolese, Negrete, Tempier & Gill, 2006), more hospitalisations (Haywood et al., 1995), poorer treatment compliance (Owen et al., 1996; Miller, 2008), higher relapse rates (Lambert et al., 2005; Malla et al., 2008; Lambert et al., 2008) and higher costs for mental health services (Bartels et al., 1993) than patients with a single psychotic disorder. On-going substance abuse has also been shown to be related to levels of depression (Margolese et al., 2006).

Few studies have identified interventions that reduce cannabis use for example and improve clinical outcome amongst this population. Interestingly patients with comorbidity who were treated for their psychiatric illness have been found to show a reduction in psychotic symptom scores over 12 months, even when their substance use remained largely unchanged (Margolese et al., 2006). Integrated treatment for both conditions however has not been proven to be so successful.

In a recent multi-centre, randomised-controlled trial of a group psychological intervention (based on CBT and Motivational Interviewing) for psychosis with comorbid cannabis dependence Lawlor et al. (2012) found that at 3-month and 1-year follow-ups no intervention effect on cannabis use, symptoms, global functioning, insight or attitude to treatment was found.

Although the intervention improved subjective quality of life at 3 months and this effect was sustained at 1 year, neither psychotic diagnosis nor type of substance abuse diagnosis was found to be related to outcomes for dual diagnosis treatments. However, dual diagnosis treatments was found to be successful in reducing hospitalisation and homelessness (Xie, McHugo, Helmstetter & Drake, 2005).

Substance-abuse-only-focused-treatment has in some studies been found to be successful, with significant improvements in proximal

outcomes (e.g. approach to coping) and in distal outcomes (e.g. psychiatric symptoms, substance use frequency etc.) up to 5-years later (Boden & Moos, 2013).

A study looking at the role of medication in patients with co-occurring psychosis and substance use disorder (Hunt & Bergen, 2002) found that patients who were compliant with antipsychotic medication, but also abused substances, were readmitted to hospital sooner (within 10 months of first admission). Over a four year period, non-compliant substance abusing patients made up 57% of all readmissions, leading to the conclusion that any benefit from antipsychotic medication compliance in reducing readmission was counteracted by on-going substance abuse.

A recently published Barcelona-based study investigating the influence of substance use disorders on readmission risk in inpatients with first-episode psychosis found that a quick screening self-report scale for cannabis and cocaine use disorders was a significant predictor (compared to urinary analysis) for predicting readmission in the first five years after initial episode (Batalla et al., 2013). This study highlights the need for more longitudinal research examining screening tests for substance use in the early phases of psychotic illness to be conducted to evaluate their benefits in preventing early readmission in first-episode psychosis.

In a systematic review of substance use disorders in first-episode psychosis Wisdom, Manuel and Drake (2011) found that few studies examined mental health outcome as well as substance use outcome. Only including studies examining FEP, as well as comorbid substance abuse, dependence and substance use disorder, the authors identified nine studies that described outcomes from psychiatric-only treatment for individuals with co-occurring disorders and five studies that described outcomes from integrated treatments.

**Table 1: Summary of findings from studies of first-episode psychosis treatment with or without specialised substance abuse treatment**

Study	Substance use outcome	Mental health outcome	Functional outcome
<i>Without specialised substance abuse treatment</i>			
Archie et al., 2007	Improvement <sup>a</sup>	No change	No change
Baeza et al., 2009	Mixed findings	Improvement	Not assessed
Grech et al., 2005	Improvement	Mixed findings	Not assessed
Harrison et al., 2008	Improvement	Mixed findings	No change
Kovaszny et al., 1997	Observational only	No change	Observational only
Lambert et al., 2005 and Hinton et al., 2007	Improvement	Improvement	Not assessed
Turkington et al., 2009	Improvement	Observational only	Observational only
Verdoux et al., 2001	Improvement	Not assessed	Not assessed
<i>With specialised substance abuse treatment</i>			
Addington et al., 2001	Improvement	No change	Mixed findings
Carr et al., 2009	Improvement	Not assessed	Not assessed
Edwards et al., 2006	No change	No change	No change
Gleeson et al., 2009	No change	Improvement	No change
Kavanagh et al., 2004	No change	Not assessed	Not assessed

<sup>a</sup> "Improvement" indicates the intervention group demonstrated a statistically significant increase in positive outcomes or a decrease in negative outcomes compared with the comparison or control group. "Mixed findings" indicates improvement on some measures of the outcome and no difference or negative findings on other measures of the outcome.

Reprinted from: "Substance Use Disorder Among People With First-Episode Psychosis: A Systematic Review of Course and Treatment" by Jennifer P. Wisdom, Jennifer I. Manuel & Robert E. Drake, 2011, *Psychiatric Services*, 62:9, p. 1009. doi: 10.1176/appi.ps.62.9.1007.

The findings as to the effectiveness of substance abuse treatment for comorbid patients were mixed. As Table 1 shows, several of the cohort FEP studies documented significant reductions in both drug (mainly cannabis) and alcohol use in the absence of specialised substance abuse treatments.

Some studies found that clients diagnosed as having substance dependence or greater depression (Turkington et al., 2009) at baseline were more vulnerable to persistent substance use disorders, but only a few studies compared patients with substance use cessation to those with substance use continuation. Wisdom et al. (2011) found in one study significant differences in involuntary hospitalisations and arrests between drug abusers and non-abusers at baseline; however these differences were no longer significant at follow-up (Archie et al., 2007). An interesting finding was that in many of the studies patients who adopted abstinence reduced their rates of relapse and hospitalisation, whereas those who continued to abuse substances experienced increased rates of relapse and hospitalisation.

Apart from the lack of power in any of these studies, Wisdom et al. (2011) argue that a possible explanation of these findings is that a significant proportion of patients who were using or abusing alcohol and other drugs may have reduced their substance use or became abstinent when they experienced a first episode of psychosis as a result of the traumatic experience of a psychotic experience itself and/or the education they received about preventing relapses (Drake et al., 2011).

Alternatively, they argue that while treating psychosis some reduction in substance abuse was attained through the common therapeutic elements typically found in treatments for psychosis and substance abuse (e.g. assertive outreach, comprehensiveness, long-term perspective, shared decision making, stage wise treatment and pharmacotherapy); a clear rationale for integrated treatments for dual diagnosis (Mueser, Drake & Noordsy, 1998).

## **2.4 WHY IS ETHNICITY OF INTEREST?**

### **2.4.1 Ethnic differences in risk for psychosis and pathways to care in psychotic populations**

Research in FEP populations has shown considerable ethnic differences not only in incidence but also in pathways to mental health service care.

Much of this research has focused on differences between Black (Caribbean and African) and White patients. Early research examining incidence rates in psychotic disorders in ethnic minorities showed growing evidence of elevated rates of schizophrenia and other psychotic illnesses (Hutchinson, Mallett & Fletcher, 1999) and mania (Sharpley et al., 2001) amongst African-Caribbeans.

The same pattern was observed in more recent studies examining first and second generation immigrants from several ethnic backgrounds who both had an elevated risk for non-affective and affective psychoses. Although this varied by ethnicity, the risk of psychoses in first and second generations of the same ethnicity were estimated to be roughly the same (Coid et al. , 2008).

There is also mounting evidence of ethnic differences in the pathways to and utilisation of mental health services (Rwegellera, 1980). A three-centre UK-based study (which forms the foundation of this PhD study) of first-episode psychosis suggested that Black Caribbeans are less likely to seek help from a GP, as well as less likely to be referred to specialist services when they do; a finding which has significant implications for early detection of psychosis at a primary care level (Morgan et al., 2004).

In addition, numerous UK-based studies have found that Black Caribbean and Black African patients are more likely than White patients to come into contact with mental health services in a compulsory capacity. These contacts often involve the police and other criminal justice agencies (Bhui et al., 2003) and appear to follow more coercive and complex routes to psychiatric care (Commander et al., 1999).

An early study has shown that Black Caribbeans may also experience longer periods of untreated psychosis (Harrison et al., 1989) however subsequent research has found not this to be the case (Cole et al., 1995; Morgan et al., 2006).

#### **2.4.2 The relationship between ethnicity and clinical/social outcomes in psychosis**

Unlike research around ethnic differences at first presentation of psychotic illness, research over the last decade regarding ethnic differences in outcomes of patients with FEP has been mixed.

A systematic review of outcome and ethnicity in FEP populations (Chorlton, McKenzie, Morgan & Doody, 2011) showed considerable variations in findings. Focusing on follow-up studies ranging from four years nine months to ten years after first admission, the review included all studies with FEP populations between 1950 and 2010 using prospective and retrospective methodologies.

One study found that Black Caribbeans tended to be sporadic attendees of community services compared to other ethnic groups (McGovern & Cope, 1991). However, several studies have found that contact with services at follow-up did not differ by ethnic group (Goater et al., 1999; McGovern et al., 1994; Mohan et al., 2006).

While some studies reported that Black Caribbean patients were more likely to have experienced multiple compulsory admissions compared to white patients (Takei et al., 1998; McGovern et al., 1994), two others reported no association between type of hospital admission and ethnicity (Goater et al., 1999; Harrison et al., 1999).

Again findings for length of admission were mixed. A handful of studies reported no association between ethnicity and length of admission (Callan, 1996; Harrison et al., 1999; McGovern et al., 1994) or total time as an inpatient (Harvey et al., 1990; McKenzie et al., 1995 & 2001). Others however reported that length of time as an inpatient was higher in Black Caribbean groups compared to White groups (Harrison et al., 1999) and Black Caribbean patients with schizophrenia had a significantly higher median length of hospital admissions compared with White patients in others (Takei et al., 1998).

With regard to social functioning, and with the exception of one study which reported that Black Caribbeans had higher levels of employment than Asian and White groups during the follow-up period (Birchwood et al., 1992), most studies reported no significant association between social functioning and ethnicity (Harrison et al., 1999; McGovern et al., 1994; McKenzie et al., 1995, 2001; Sugarman, 1992), 'social recovery' and ethnicity (Harvey et al., 1990) and ethnicity and social circumstances at outcome, including employment (Goater et al., 1999; McGovern et al., 1994; McKenzie et al., 1995) and type of accommodation (Goater et al., 1999; McGovern et al., 1994; McKenzie et al., 1995).

Chorlton et al. (2011) also found that the studies included in the review reported no significant differences between course of psychotic symptoms and ethnicity (Goater et al., 1999; Harrison et al., 1999), between symptom recovery between episodes and ethnicity (Birchwood et al., 1992) or between ethnicity and positive symptoms (McGovern et al., 1994).

With the exception of one study that found higher rates of negative symptoms in White patients (Callan, 1996), the majority of studies that examined negative symptoms found no significant differences in frequency among ethnic groups (Goater et al., 1999; Harrison et al., 1999; McGovern et al., 1994; McKenzie et al., 1995; Perera et al., 1991; Takei et al., 1998).

There are two things that are noteworthy when interpreting the usefulness of these results. Firstly, Chorlton et al. (2011) highlight the severe heterogeneity of the studies selected for inclusion with differences in definition of FEP, method of data collection, length of follow-up and follow-up rate, sample size, categorisation of ethnicity, adjustment for confounding variables, geographical area and types of assessments used to measure outcome. Secondly, despite a predominance of negative findings for the ethnic differences in clinical and social outcome in psychotic populations, it is unclear whether ethnic differences may occur when individuals have comorbid substance use disorders.

#### **2.4.3 Ethnic differences in the prevalence of substance use in the general population**

In addition to ethnic differences in the prevalence of psychotic disorders in the general population and pathways to mental health care there are well-documented differences in the prevalence of substance use in the general population (Karlsen, Rogers & McCarthy, 1998; Canning et al., 1999; Galea, Nandi & Vlahov, 2004) with people from non-White ethnic backgrounds being significantly more likely to abuse cocaine (Vivancos et al., 2006) and people from White backgrounds more likely to abuse alcohol (Grant et al., 2004).

In minority ethnic populations, studies have shown higher levels of drug use among African Caribbeans than among Indians and



Pakistanis/Bangladeshis and these differences were amplified in people aged between 16 and 29 years (Ramsey & Spiller, 1997).

A study by Leitner et al. (1993) found that in one geographical location over half the White respondents had taken illicit drugs compared to only one third of the Black respondents. Substance use among Black Caribbeans often centres on crack-cocaine use and cannabis use, although low levels of substance use have been found in Black African populations (Aust & Smith, 2003).

Interestingly findings from the 2001/2002 British Crime Survey have shown that prevalence of cannabis use in the previous year was higher in the Black Caribbean than in the White British population (Black Caribbean 17% vs. White British 11%). However, lifetime ever prevalence of cannabis use was roughly the same in both ethnic groups (Black Caribbean 33% vs. White British 30%), (Aust & Smith (2003).

The prevalence of heroin use in the Black Caribbean community has been estimated to range between 2% and 4% (Castleton & Francis, 1996) and alcohol consumption and alcohol-related problems in UK Black Caribbeans has been reported to be comparatively lower than in Whites (Balarajan & Yuen, 1986). Khat (a drug with stimulant properties) has been found to be widely used in some African communities, such as UK Somali (Williams & Nutt, 2005).

More recently a paper by Wanigaratne, Dar, Abdulrahim & Strang (2003) which reviewed the relationship between ethnicity and drug use in the UK noted findings from the British Crime Survey which indicated that drug use is more widespread among Whites than within any other ethnic group. National reports have shown that in general, overall drug use has been found to be lower among minority ethnic groups than among White groups. Reported cannabis use prevalence has found to be highest in groups from mixed ethnic backgrounds in a number of studies, however, when adjusted for age this groups drug use levels are similar to those in the White population (UK Drug Policy Commission, 2010).

Other findings from the UK Drug Policy Commission (2010) have shown poly drug use is most common among White groups, compared with other ethnic groups. National and local records of treatment services, and some small scale studies, indicate that the types of drugs that cause individuals to seek help vary between different communities. For example, among the Asian community the most common reason for seeking treatment is problematic use of heroin, whereas almost half of people from White, Mixed and Black ethnic groups report alcohol use prior to entering treatment compared with only about a third of those of Asian background.

Wanigaratne et al. (2003) have critiqued much of the research around ethnicity and illicit drug use for having small sample sizes in select groups (such as university students) that may not be representative of larger populations. The lack of valid conceptual and operational definitions alcohol or drug use (Wanigaratne et al., 2003), inconsistent use of the terms ethnicity, minority and race (McKenzie & Snowcroft, 1994) as well as credible and accurate measurement of such concepts have been identified as a problem in these studies. The UK Drug Policy Commission (2010) suggests caution in interpretation of these findings as much of this evidence comes from qualitative studies and discussions with users and community members and may not be completely representative.

Nevertheless, these findings may suggest not only ethnic differences in substance use disorders in the general population but that similar patterns may also be evident in psychotic populations, compromising a good prognosis for both disorders in minority groups.

#### **2.4.4 Ethnicity and social disadvantage**

Bhui et al., (2005) argue that "Race" is socially constructed with little biological validity. They also argue that race as a risk factor may not

fully explain ethnic differences in health and health outcome. Recent research has focused on uncovering the socio-economic mechanisms that underpin the relationship between ethnicity and both mental illness and substance use or use disorders.

A study by Morgan et al., (2008) has shown that patients with psychosis had significantly more social disadvantage (social disadvantage indicated by level of education, employment status, living arrangements, housing, relationship status and social networks) than controls. They also found White British and Black Caribbean cases, relative to their respective controls, both experienced significantly raised levels of social disadvantage and isolation. However, on several of the indicators, social disadvantage and isolation were more prevalent in the Black Caribbean population (current unemployment, living in rented housing, living alone, being single and never having had a long term relationship).

In addition social disadvantage and isolation have been explored as possible explanations for ethnic differences in the risk and prevalence of substance use in minority populations. The extent to which the strength of the association between social disadvantage and drug abuse directly relates to Black and ethnic minority groups however is yet to be properly established (Wanigaratne et al., 2003).

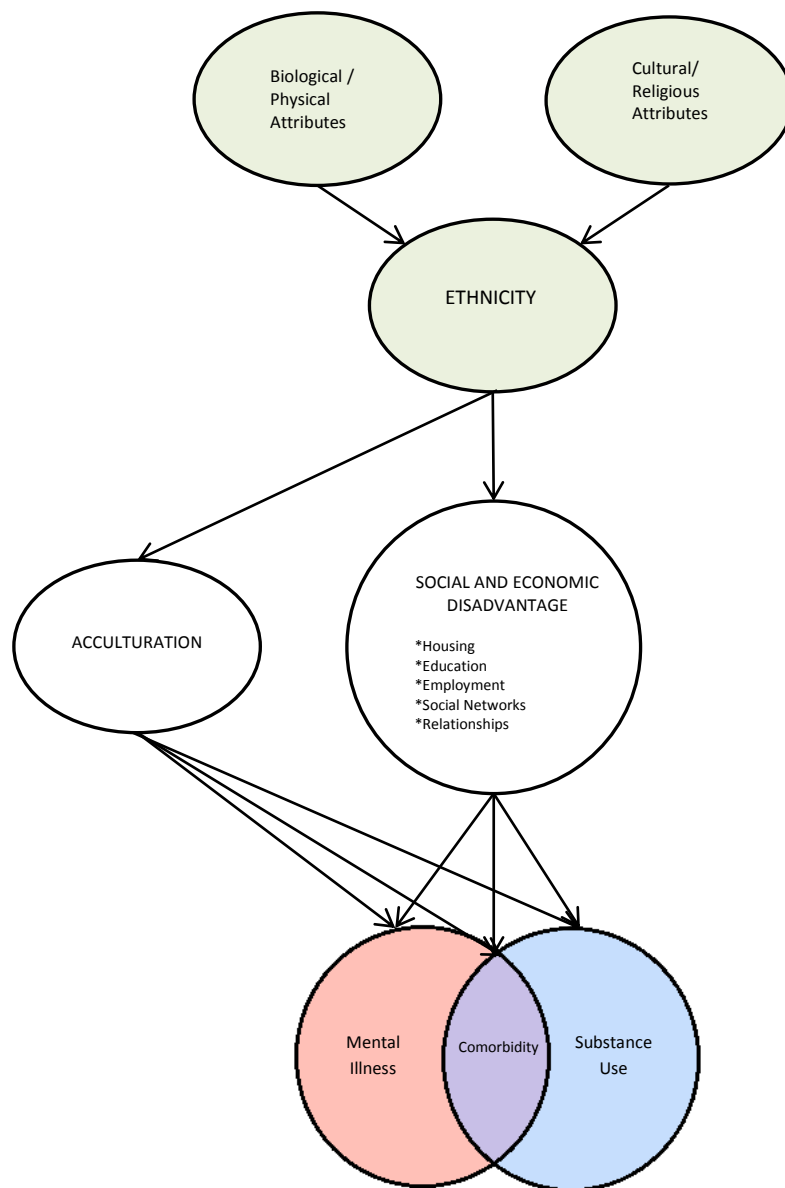
Recent examination of drug and alcohol use in the UK (The U.K. Drug Policy Commission, 2010), however has uncovered several reasons for ethnic differences. For example, peer pressure has been observed as an important reason why young people use drugs. Studies have suggested that drug use in young minority populations may be in part due to young people growing up under the influence of western culture and trends may seek to distance themselves from 'traditional' cultural values in order to 'fit in' (Fountain, 2009). Other research has suggested that BME communities may be at risk of drug use because they often live in disadvantaged and deprived areas, where drug markets thrive (Bashford et al., 2003).

Similarly several minority ethnic groups, in particular refugees and asylum seekers, often face high levels of unemployment, isolation and social exclusion (Nabuzoka and Badhadhe, 2000). Limited opportunities can lead to frustration, boredom and anxiety increasing the likelihood of drug use (Bashford et al., 2003). High levels of cannabis use within Black ethnic communities have also been explained in terms of: perceptions that cannabis is a safer drug; a history of cannabis use within the family; for Rastafarians, cannabis use is a spiritual act and part of the 'culture' of the movement (Fernandez, 2002; Sharp & Budd, 2005; Fountain et al., 2009a-e).

Figure 2 highlights how ethnicity might be linked to social disadvantage and risk factors for mental illness and substance use disorders. Here, ethnicity which combines biological or physical attributes as well as the cultural/social or religious attributes, is a risk factor for various forms of social disadvantage. This social disadvantage in turn is a risk factor for mental illness and/or substance use disorders.

What we also see from the figure below is that social disadvantage might play only part of the mediating role in the relationship between ethnicity and poor health outcomes such as mental illness or substance use disorders. Acculturation has been defined as a multidimensional concept reflecting complex processes of adaptation to a new country, society and culture (Ortega et al., 2000). It has been found to impact on risk of mental disorder (Ortega and Rosenheck, 2000) and substance use disorders (Amaro et al., 1990), though results have not been entirely consistent (Burnam et al., 1987; Fabrega and Wallace, 1970; Vega et al., 1998)'.

**Figure 2: Schematic of the relationship between ethnicity and social disadvantage.**



Acculturation, assessed through preferences for spoken and written language, personal assessment of nationality, and personal and parental nativity (e.g. Burnam et al., 1987; Ortega and Rosenheck, 2000) has been investigated by Ortega et al., (2000). Comparing three Hispanic ethnic sub groups (Mexican American, Puerto Rican and Other Hispanic), the study found that Mexican Americans who spoke English as

a first language at home as a child were more likely to have 3 or more disorders (including psychiatric and substance use disorders) compared with those who did not speak English. Similarly persons from 'other' Hispanic ethnic groups that were U.S. born or whose current language at home was English were more likely to have any psychiatric or substance use disorder.

The above study concluded that acculturated Hispanics of different nationalities have an increased risk for both psychiatric and substance use disorders than their less acculturated counterparts.

What these studies suggest is that while ethnicity may be a predictor of risk for certain psychiatric disorders, outcomes in mental illness and increased rates of substance use disorders in the general population, this relationship should be considered within the wider context of socio-economic and cultural issues experienced by minority populations.

## **2.5 CONSIDERATIONS AND LIMITATIONS OF PREVIOUS EPIDEMIOLOGICAL RESEARCH**

### **2.5.1 Additional risk for poor outcomes?**

From the research described previously it is clear that substance use is highly prevalent in psychotic populations and that patients with a comorbid substance use disorder are more likely to have negative outcomes; such as more frequent hospital admissions and more psychotic relapses.

It is also clear that patients from Black Caribbean ethnic groups are at increased risk of having a psychotic disorder and of using certain illicit substances. What isn't clear is whether increased risk of psychosis and certain types of substance use in the general population equates to

increased risk of substance use disorders in psychotic populations in patients from a Black Caribbean ethnic background.

Additionally, if we know that comorbidity is related to poorer outcome (such as compulsory admission and illness relapse) in psychotic populations and that outcome in patients with psychosis also differs by ethnicity, can we infer that certain ethnic groups with a comorbid diagnosis will have an even more elevated risk of negative outcome compared to others?

### **2.5.2 Methodological considerations**

As with many epidemiological studies of first-episode psychosis study sample size is often a problem. This is even more the case when studies have sought to uncover ethnic differences. When we look specifically at studies of pathways to care there is a difficulty in interpreting findings because previous contacts with services (that may or may not have resulted in treatment) may confound results. In addition, the data sources (most often case notes), and heterogeneity of instruments used to collect details of psychopathology and service use makes comparisons between studies and general conclusions difficult.

When studies have estimated prevalence of comorbidity they have relied on the ability of practitioners to identify, classify and record details of patients with comorbid substance use problems. However, as I will discuss in the next chapter, there is often no consensus on how they define 'dual diagnosis' (Todd, 2004).

When we examine studies that have sought to investigate ethnic differences we see that categorisations are often crude, ill-defined and inconsistent and as Morgan et al. (2004), notes the choice of ethnic categorisation may obscure important differences between groups (Singh, 1997; McKenzie & Crowcroft, 1994).

## 2.6 CONCLUSIONS

Despite methodological inconsistencies in the measurement of comorbidity, we can see from this literature that rates of comorbid substance use disorder in psychotic populations vary by country with prevalences estimated as high as 70%. Furthermore comorbidity is associated with various negative outcomes including more frequent relapses and more frequent hospitalisation. Few studies have found beneficial interventions for people with dual diagnoses despite integrated treatment approaches.

People from minority ethnic groups are at an increased risk for psychotic disorders compared to whites. They are also more likely to use certain illicit drugs suggesting that there might be an increased likelihood for comorbid diagnoses among minority ethnic populations, specifically people with Black Caribbean ethnicity. This notion forms the rationale for the systematic review outlined in the next chapter.

### Chapter Summary 2.

Chapter Summary
<p><u>Aims of the Chapter:</u></p> <p>To build on the rationale for the PhD study by providing a critical review of epidemiological research in the area of comorbid substance use disorders in first episode psychosis (FEP). In relation to the aims and objectives of the PhD study the chapter addressed the question why ethnicity should be of interest in epidemiological research in this area.</p> <p><u>Key Points:</u></p> <ul style="list-style-type: none"><li>• Prevalence's of comorbidity vary between countries</li><li>• Comorbidity is associated with various negative outcomes</li><li>• People from minority ethnic groups are at an increased risk for psychotic disorders compared to whites</li><li>• There are ethnic differences in the types of illicit substances used.</li></ul>



## **CHAPTER 3: ETHNICITY AND COMORBID PSYCHOSIS AND SUBSTANCE USE DISORDERS**

### **3.1 INTRODUCTION**

As discussed in Chapter 2, reports have shown high rates of psychosis among the Black Caribbean and Black African populations (Sharpley M. S., Hutchinson G., McKenzie K. et al., 2001), not to mention numerous studies showing these groups to be at greater risk of compulsory admission to hospital (Morgan et al., 2004; Morgan et al., 2005; Bhui et al., 2003).

Prevalence of illicit drug use in the general population has been observed to differ between and within ethnic groups as well (Aust & Smith, British Crime Survey 2001/2002), with suggestions that drug use in Black African groups is lower than in Black Caribbean or White ethnic groups and that drug use between Black Caribbean and White groups are similar (Aust & Smith, 2003).

As we saw in section 2.2 studies have documented comorbidity to be associated with a greater likelihood of admission to hospital and poorer outcomes (including worsening psychiatric symptoms; increased use of institutional services; poor medication adherence; and contact with the criminal justice system) in both mental health and drug abuse treatment services (Hunt et al., 2002).

Much of the epidemiological evidence surrounding comorbidity comes from the USA (Carra et al., 2009). The Epidemiologic Catchment Area (ECA) being one of the largest studies of this type, found that 47%

of people with schizophrenia had a comorbid substance use disorder, with odds of meeting criteria for such a disorder 4.6 times higher for individuals with schizophrenia than for the rest of the US population (Regier et al., 1990). It has been reported that Black psychiatric patients are more likely to receive a comorbid psychiatric diagnosis compared to Whites (Febrega et al., 1989), however this was not found in the ECA study (Regier et al., 1990).

However, there is very little evidence regarding the relationship between comorbid psychosis and substance use disorders and ethnicity internationally or in the UK. Consequently very little is known about the prevalence, characteristics of and outcomes for these groups which have implications for policy and practice in the mental health and substance abuse treatment fields. The purpose of this review is to investigate whether there is evidence of ethnic differences in the prevalence and outcomes of patients with comorbid psychosis and substance (drug or alcohol).

## **3.2 METHOD**

### **3.2.1 Search strategies**

Literature searches were conducted within the following four sources. A search term strategy was used for searching each source (see appendix 2).

#### **1. Electronic databases<sup>1</sup>:**

OVID Databases (EMBASE, OVID MEDLINE In-Process and other non-indexed citations, OVID MEDLINE, AGRIS, Social Policy and Practice and

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<sup>1</sup> Each database was searched from the earliest dates available

PsychInfo) were searched. Web of Knowledge (Inspec, Medline, Web of Science, Biosis citation index and previews, and Journal citation reports), was also searched.

## 2. Web based sources

Searches were conducted using the web based search engine Google Scholar. Google Scholar is considered one of the major academic search engines (Jean-François, Laetitia & Stefan, 2013). It uses a ranking algorithm in a similar "way researchers do, weighing the full text of each article, the author, the publication in which the article appears, and how often the piece has been cited in other scholarly literature"(Google Scholar). Research into the ranking on this search engine has shown that Google Scholar puts high weight on citation counts (Beel & Gipp, 2009a) and words included in a document's title (Beel & Gipp, 2009b).

This means the first search results are often highly cited articles. Because of the strength of the search engine and the high number of possible hits that can be obtained, a more conservative collection of search terms were used for web searches. Search results were found to be duplicated after the first few search result pages. No further review of results pages were conducted when duplication became clear. Google Scholar search results report the title and the first few sentences within the paper that contain the keywords being searched for. These sentences may or may not include part of the abstract but provide enough information to determine whether a paper should be downloaded in full text to be scrutinized further.

The internet has improved the visibility of 'grey literature' however in addition to these electronic databases, the website Scirus (a website which included grey literature) was also searched using the same search term strategy as the web searches.

### 3. Reference lists of eligible papers

Once a sample of eligible full text papers had been sampled from the electronic database and web searches, the reference lists of those papers were reviewed and papers that were considered relevant to the topic area were obtained in full text for further screening for eligibility.

### 4. Personal contacts:

Key authors in the areas of comorbidity and ethnic differences in mental health were consulted for additional information on any published and unpublished studies in this area (Dr. Sarah Afuwape and Dr. Dinesh Bhugra).

### **3.2.2 Search terms**

Psychosis is an umbrella term for several psychiatric diagnoses including Schizophrenia, Schizoaffective disorder, Bipolar and Psychotic Depression. To be as inclusive as possible several terms relating to psychosis and substance use disorders were used when searching electronic databases and web searches. A full overview of the search terms used as part of the search strategy can be found in Appendix 2.

Terms were linked together using the boolean term 'and' and wild cards (the use of an asterix \* to replace unknown characters of a word that shares the same core or stem as another word e.g. schizo\* would also include schizophrenia and schizoaffective), were used where necessary.

Searches conducted in the electronic databases were done in stages: each database was searched individually; each term (which was expanded to include all formations) was entered individually and then

combined with other related terms to narrow down the results further. This process was continued until all relevant term variations for psychosis and substance use disorder and ethnicity were combined. The OVID databases allow for abstracts as well as titles of search results to be displayed. Both titles and abstracts for OVID databases were screened manually for relevance and eligibility (see below). All papers considered potentially eligible were then downloaded for further assessment of eligibility.

### **3.2.3 Study inclusion criteria and method for determining eligibility**

Comorbidity can be defined in many ways (see section 1.2.2). This review was interested in literature concerned with the comorbidity or dual diagnosis of patients with a diagnosed psychotic illness and a co-occurring substance use disorder (namely substance misuse, diagnosed abuse or dependence of alcohol or illicit drugs).

The inclusion criteria for the review were as follows:

- a) Study participants (or a sub sample of participants) had a diagnosis (either ICD-9 or -10, or DSM III IIIR, or IV), of psychosis (schizophrenia, schizoaffective disorder or bipolar disorder with psychotic features, other non-organic psychotic disorder) as well as comorbid substance (alcohol or illicit drug), misuse, diagnosable abuse or dependence
- b) Analyses reported ethnic differences in the prevalence, outcome or patient characteristics of the sample.

To be as inclusive as possible, studies that investigated comorbid substance misuse were included as well as those studies that identified diagnosable drug use disorders.

Studies investigating bipolar disorder were included as long as their sample (or part of their sample), were psychotic. This information about the sample was usually ascertained during review of the full text document. Studies which focused on mental illness in general were excluded unless they documented (e.g. through comparison) ethnic differences in the prevalence or risk of a comorbid psychotic illness with co-occurring substance use disorder.

As highlighted in the previous chapters, as well as the methodological considerations of this review, defining comorbidity can be problematic. Many epidemiological studies examine comorbid substance 'use' and either do not distinguish between those who have problematic use or a diagnosable substance use disorder or alternatively use the terms interchangeably (Barnes et al., 2006). This makes comparability of findings in this area problematic.

The exclusion criteria for the review were as follows:

- a) Studies which investigated psychopathology other than psychosis
- b) Studies that investigated non-problematic substance use or included non-problematic substance use in their definition of comorbidity
- c) Studies which did not report differences in prevalence, outcome or sample characteristics by ethnicity

All titles and abstracts produced by the searches were screened for relevance to the topic area. Full text documents were then obtained for all publications that were considered to be eligible. As mentioned above

the reference lists of papers that were considered eligible were also screened for relevance and full text papers obtained. Those papers were then subjected to screening for eligibility and a final sample of eligible papers was produced. This type of method is advocated by the Cochrane collaboration in their handbook for conducting systematic reviews (Higgins and Green, 2008).

It should be noted that this review is not a meta-analysis but a narrative review with interpretation of evidence. The number of papers identified was small and the definitions of both ethnicity and comorbidity were so varied that it was impossible to conduct a meta-analysis.

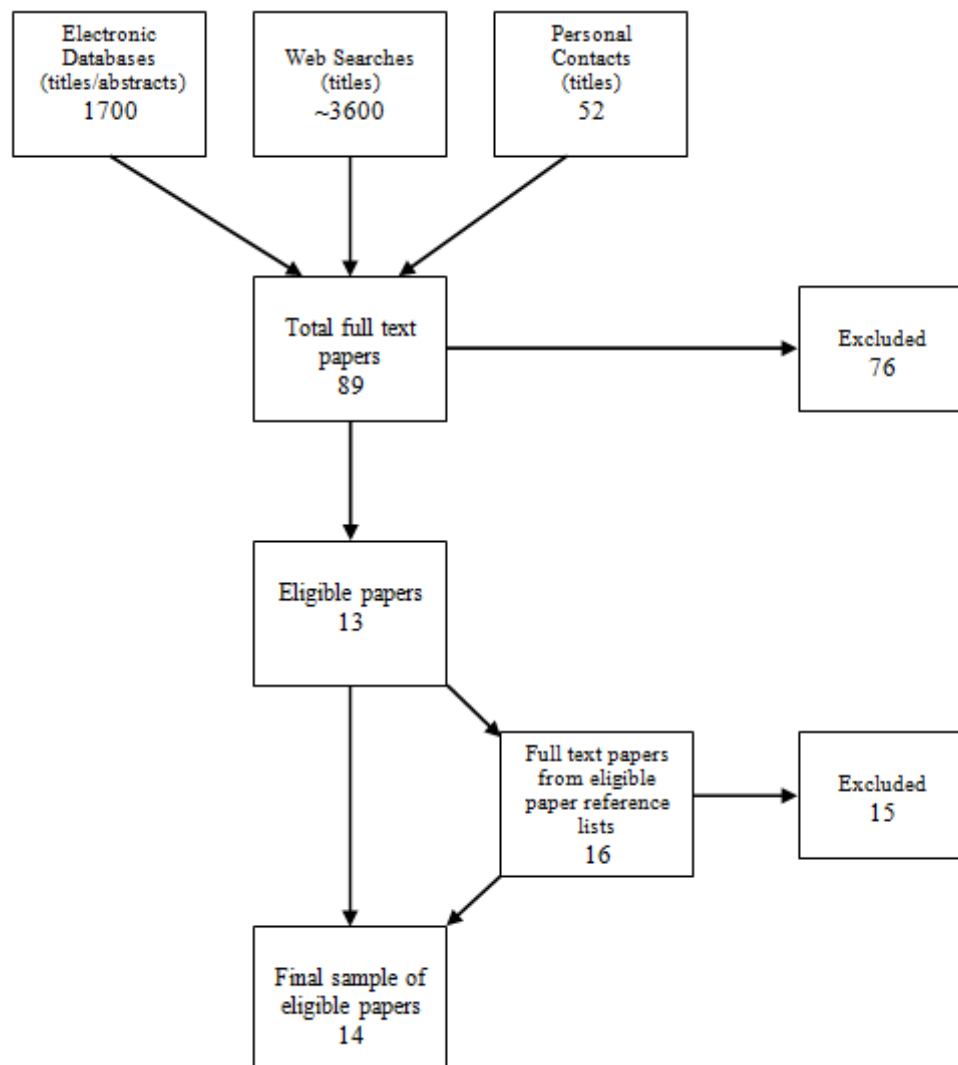
#### **3.2.4 Papers excluded from the review**

Ninety-one papers did not meet the eligibility criteria and subsequently were not included in the review (see Figure 3). Reasons for exclusion were varied. Seventy-two studies were excluded because they focused on comorbid Axis I mental illness and comorbid substance use disorders and did not present data on psychotic illness comorbidity separately and/or they did not present findings by ethnic group. Fourteen studies were excluded because their focus was on Bipolar disorder and as with the general Axis I mental illnesses did not present findings on patients with psychotic illnesses. Several studies (n=4) after review of the full text papers were found to be investigating comorbid non-problematic substance use or failed to report a consistent operationalised concept of comorbidity and so were excluded.

One of the papers obtained was a systematic review of comorbid psychosis and substance use disorders (Carra et al., 2009). Although the review by Carra et al. (2009) had similar inclusion criteria, several papers

included did not meet this reviews inclusion criteria. Subsequently this review was excluded.

**Figure 3: Flowchart showing stages for obtaining final sample of reviewed papers.**





### **3.3 RESULTS**

Fourteen studies were identified. Four studies were conducted in the UK, seven studies were conducted in the US, two studies were conducted in Europe, and one study was a systematic review of studies conducted in three different locations around the world. None of the studies were conducted in a substance abuse population. Three studies were conducted in services for dually diagnosed patients; Two studies were general population based; and the remaining studies were conducted among psychotic populations.

From a detailed analysis of all the eligible papers the collective findings can be categorised into six different areas: ethnic differences in the estimated prevalence of comorbidity; ethnicity as a risk factor for comorbidity; ethnic differences in drug choice; ethnic differences in psychiatric diagnosis and symptom severity of patients with comorbidity; ethnic differences in treatment outcome; and ethnic differences in experiences of services.

#### **3.3.1 Ethnic differences in the prevalence and correlates of comorbid substance use disorders in psychotic populations**

Evidence relating to ethnic differences in the prevalence of comorbid substance use disorders in psychotic populations was mixed. The earliest paper obtained from searches for this review was an American report by Rosenthal et al. (1992). The paper examined patterns in demographics, symptoms and substance abuse in patients with co-occurring substance use disorders and schizophrenia. The paper reported on three studies.

The first study looked at number of cases that met DSM-III criteria for substance use disorder (PSUD) in schizophrenic inpatients. The second study analysed data on schizophrenic admissions to a dual diagnosis unit and the third study assessed the benefits of integrated outpatient treatment in an early model of a dual diagnosis program – The Combined Psychiatric and Addictive Disorders Program (COPAD) at Beth Israel Medical Center (BIMC) in New York.

For the first study, all 1792 psychiatric hospital admissions were examined over a one year period (1985). Six hundred and two patients were identified as suffering from a schizophrenic disorder, and of those 24.3% (n=146) were deemed to have a co-occurring substance (drugs and ethanol) use disorder (dual diagnosis group). This dual diagnosis group consisted of three ethnic groups with nearly equal proportions of Black (34.2%), Caucasian (37%), and Hispanic (28.1%) patients.

A group of 146 non-substance abusing schizophrenic patients admitted immediately subsequent to each dual diagnosis admission was selected for comparison. A greater proportion of Hispanics were found among the dual diagnosis group than among the non-abusing schizophrenic group; the reverse was found for Caucasian patients. These patterns were not observed for African-Americans in abusing and non-abusing groups.

**Table 2: Description of Studies**

<b>Authors</b>	<b>Diagnostic Group/Sample Size</b>	<b>Method of Assessment</b>	<b>Exposed Sample* (%)</b>	<b>Measure of Comorbidity</b>	<b>Ethnic Distribution of Exposed Sample<sup>a</sup> / Prevalence of Exposure within Ethnic Groups<sup>b</sup></b>
U.K					
Cantwell et al. (1999)	FEP (n=168)	Standardised diagnostic/structured interviews (patient and key informant)	Alcohol misuse (11.7%; n=18) Drug misuse (19.5%; n=30)	Diagnosis of psychotic disorder according to ICD-10 and co-occurring substance (drug) misuse	Substance <sup>b</sup> : Non-African-Caribbean (32.0%) and- African-Caribbean (6.9%).
Miles et al. (2003) Afuwape et al. (2006)	Psychotic disorder (n=1271)	Routine clinical assessment, standardised diagnostic/structured interviews (patients and case managers) and consensus rating	16.8% (n=213)	Diagnosis of psychotic illness (schizophrenia or schizoaffective disorder, bipolar affective disorder, or delusional disorder) according to ICD-10 and co-occurring abuse, dependence or dependence with institutionalisation of drugs and/or alcohol.	Alcohol only <sup>a</sup> : White 68%; Black 23%; and other 9% Cannabis only <sup>a</sup> : White 17%; Black 79%; and Other 3% Alcohol only <sup>b</sup> : White, 15%, n=101; Black Caribbean, 5%, n=11; Black African, 14%, n=11; Black British 23% n=27 Cannabis only <sup>b</sup> : White, n=42, 6%; Black Caribbean, n=15, 7%; Black African, n=12, 10%; Black British, n=46, 40% Stimulant only <sup>b</sup> : White, n=25, 4%; Black Caribbean, n=6, 3%; Black African, n=5, 4%; and Black British, n=13, 11%
Warfa et al. (2006)	Dually diagnosed (n=9)	Self report	100%	Diagnosis of Schizophrenia, Bipolar Affective Disorder, Severe Personality Disorder, and problematic or harmful use of psychoactive substances including prescription drugs or	Substance <sup>a</sup> : White British (n=3); Black Caribbean (n=2); Somalian (n=2); Ethiopian (n=1); and Mixed Ghanaian and Scottish (n=1)

**Table 2: Description of Studies**

<b>Authors</b>	<b>Diagnostic Group/Sample Size</b>	<b>Method of Assessment</b>	<b>Exposed Sample* (%)</b>	<b>Measure of Comorbidity</b>	<b>Ethnic Distribution of Exposed Sample<sup>a</sup> / Prevalence of Exposure within Ethnic Groups<sup>b</sup></b>
				Alcohol.	
USA					
Rosenthal et al. (1992)	Schizophrenia (n=602) Dual Diagnosis (n=30)	Routine clinical assessment and standardised diagnostic/structured interviews (patients)	Study 1: 24.3% (n=146) Study 3: 100% (n=30)	Diagnosis of substance (drugs and ethanol) use disorder and schizophrenia according to DSM-III criteria	Study 1 <sup>a</sup> : Caucasian (37%), Black (34.2%), and Hispanic (28.1%) Study 3 <sup>a</sup> : White (Caucasian) (33.3%); Black (36.3%); and Hispanic (30.0%).
Strakowski et al. (1992)	Psychotic Disorders (n=173)	Case note review of administrative data based on routine clinical assessment	Alcohol abuse (27.2%; n=47); Drug abuse (20.2%; n=35)	Diagnosis of a primary psychotic disorder (Schizophrenia, Schizoaffective Disorder; Bipolar Affective Disorder with psychotic symptoms; Unipolar Major Depression with Psychotic Symptoms; Atypical Psychotic Disorder) with co-occurring Alcohol abuse or Drug abuse according to DSM-III-R.	Alcohol only <sup>a</sup> : Black (30%); White (26%); Drug only <sup>a</sup> : Black (23%); White (19%)
Jerrell and Wilson (1996 and 1997)	Dually diagnosed (n=100)	Standardised diagnostic/structured interviews (patients)	100% (n=100)	Diagnosis of schizophrenic type disorders (schizophrenia or schizoaffective) with co-occurring substance use disorder according to DSM-III-R	Substance <sup>a</sup> : White (n=69) and Ethnic (n=31)
Mueser et al. (2001)	Psychotic disorders (n=161)	Standardised diagnostic/structured interviews (patients)	Not specified	Diagnosis of schizophrenia, schizoaffective disorder, or bipolar disorder with a co-occurring diagnosis of substance (drug or alcohol) abuse or dependence according to	Not specified

**Table 2: Description of Studies**

<b>Authors</b>	<b>Diagnostic Group/Sample Size</b>	<b>Method of Assessment</b>	<b>Exposed Sample* (%)</b>	<b>Measure of Comorbidity</b>	<b>Ethnic Distribution of Exposed Sample<sup>a</sup> / Prevalence of Exposure within Ethnic Groups<sup>b</sup></b>
				DSM-III-R or DSM-IV	
Copeland et al. (2003)	Schizophrenia (n=69,787)	Case note review of administrative data based on routine clinical assessment	27% (n= 18,842)	Diagnosis of Schizophrenia and co-occurring substance use disorders/substance abuse	Substance <sup>b</sup> : African American (38%); Hispanic (23%); White (22%)
Ahuja et al. (2007)	Schizophrenic Disorders (n=3'950**)	Case note review of administrative data based on routine clinical assessment	Substance (Drug) Related Mental Disorder (27%; n=1,082); Alcohol Related Mental Disorder (10%; n=394)	Diagnosis of schizophrenia with co-occurring substance related and alcohol related mental disorders according to ICD-9-CM (drug psychoses; drug dependence; non-dependent abuse of drugs; alcohol psychoses; alcohol dependence syndrome; and alcohol abuse).	Drug only <sup>a</sup> : African American/Black (63.7%); Caucasian/White (27.2%) Alcohol only <sup>a</sup> : African American/Black (64.7%); Caucasian/White (23.9%)
<b>Other</b>					
Cantor-Graae et al. (2001) (Sweden)	Schizophrenia (n=87)	Routine clinical assessment, standardised diagnostic/structured interviews (patients and) consensus rating and case note review	48.2% (n=42)	Diagnoses of schizophrenia and co-occurring diagnosis of substance abuse or dependence according to DSM-IV	Not specified
Veen et al.	FEP	Routine clinical	26%; n=47	Diagnosis of psychotic disorder	Drug only <sup>b</sup> : Dutch (23%); Moroccans

**Table 2: Description of Studies**

<b>Authors</b>	<b>Diagnostic Group/Sample Size</b>	<b>Method of Assessment</b>	<b>Exposed Sample* (%)</b>	<b>Measure of Comorbidity</b>	<b>Ethnic Distribution of Exposed Sample<sup>a</sup> / Prevalence of Exposure within Ethnic Groups<sup>b</sup></b>
(2002) (Netherlands)	(n=179)	assessment, standardised diagnostic/structured interviews (patients and case managers) and consensus rating		(Schizophrenia, schizophreniform, schizoaffective disorder, mood disorder with psychotic features, delusional disorder, brief psychotic disorder, shared psychotic disorder or psychotic disorder not otherwise specified) according to DSM IV with co-occurring substance (drug) misuse in the previous year.	(17%); Surinamese (27%); Turkish (30%); Others (33%)
McLean et al. (2012) (Australia, India and Sarawak)	Schizophrenia: Australia (n=821); India (n=520); Malaysia (n=298).	Standardised diagnostic/structured interviews (patients and relatives) and case note review	Not Applicable	Diagnosis of schizophrenia or schizoaffective disorder and co-occurring substance abuse or dependence according to DSM-IV	Cannabis only <sup>b</sup> : Australia (45.5%); India (0%); Sarawak (0.8%) Other drug only <sup>b</sup> : Australia (26.5%); India (0.0%); Sarawak (2.6%) Alcohol only <sup>b</sup> : Australia (40.7%); India (0.8%); Sarawak (10.5%)

\*Patients with both psychosis and substance use disorder as defined by the study. \*\*unduplicated cases for 2003 only

The second study focused on sociodemographic and clinical characteristics of a sample of 457 consecutive admissions to a Psychiatric Substance Abuse Inpatient Unit during 1989. Of these, 106 (23%) inpatients were diagnosed with DSM-III-R schizophrenia (or schizoaffective disorder). Although examination of the ethnic distribution of the sample was conducted: Caucasian (29.8%); Black (28.9%); Hispanic (33.0%); and Asian (<2%), these analyses were not conducted on the subsample of dual diagnosis patients with schizophrenic (or psychotic) disorder.

The third study which assessed the COPAD program conducted at the Psychiatric Substance Abuse inpatient unit of BIMC compared integrated and non-integrated outpatient treatment of PSUD schizophrenic patients. The inclusion criteria for the programme were: patients aged between 18-50 years; a Research Diagnostic Criteria diagnosis of schizophrenia-continuum disorder, concurrent DSMIII-R psychoactive substance abuse/dependence (PSUD) and an expressed desire for substance abuse treatment. Thirty patients took part in the program. Similarly to the first study the sample was split equally between three ethnic groups; White (Caucasian) (33.3%); Black (36.3%); and Hispanic (30.0%). No further analyses were conducted with regard to sensitivity of diagnosis, symptom severity, patterns of substance abuse or treatment outcomes.

Although this early paper shows higher prevalence of Hispanic patients in substance abusing schizophrenic populations compared with non-substance abusing schizophrenic populations, several critiques however can be made. Firstly, the first and third studies did not conduct statistical tests to see if ethnic differences were significant. In addition, the non-abusing group (control group) in the first study was not selected randomly.

The authors note that since the diagnostic criteria and methods of data collection differed between studies, comparability is limited. For

example, they highlight that while routine clinical assessment and standardized structured interviews were used consistently between studies to determine schizophrenia spectrum disorders, the measures used to determine substance abuse were not. Study One revealed that 11% of schizophrenics were DSM-III substance abuse/dependence diagnosed while Study Three yielded a 90% dual diagnosis sample.

An early 90s US study investigated the effects of race and comorbidity on clinical diagnosis in patients with psychosis (Strakowski et al., 1993). Retrospective clinical review of 231 case records of a large public hospital in Tennessee USA was conducted. They found that 173 patients (74.9%), met criteria for a primary psychotic disorder according to DSM-III-R criteria in discharge summaries. Comorbidity was defined as a non-primary diagnosis of an Axis I or Axis II disorder and was categorised into three groups: Drug abuse; Alcohol abuse; and any other psychiatric disorder.

Comorbid drug abuse was diagnosed in 20.2% (n=35) of patients and comorbid alcohol abuse was diagnosed in 27.2% (n=47) patients. There were no statistically significant differences in the prevalence of comorbid alcohol (Black patients, 30.4%; White patients, 25.6%) and drug (Black patients, 23.2%; White patients, 18.8%) abuse between Black and White patients.

Further analyses were done on a sub-sample of patients who had been discharged from their first hospitalisation (n=39). Analyses were performed on this sub-sample, examining ethnic differences for those with and without a schizophrenic psychotic disorder in terms of comorbidity. Although ethnic differences in prevalence of comorbid alcohol (for example Black Schizophrenics, 42.9% vs. White Schizophrenics, 20.0%) and comorbid drug abuse (for example Black non-Schizophrenics, 0% vs. White non-Schizophrenics 25%) between these two psychotic groups was observed, the numbers were too small of statistical analyses or meaningful interpretation (Strawkowski et al., 1993).



Jerrell and Wilson (1996 & 1997) examined ethnic differences in White and ethnic minority clients' psychosocial functioning, psychiatric and substance abuse symptomatology from a clinical trial examining the relative cost effectiveness of three specialized interventions for dual disorders (Behavioural skills training, case management, and a 12-step recovery model). Clients in the study were adults, aged between 18 to 59, who had an Axis I DSM-III-R diagnosis with a co-occurring substance disorder and had undergone psychiatric treatment one or more times in an inpatient facility.

They found that White clients made up the biggest proportion of service users (n=92, 70%). Ethnic minority clients fell into 4 different groups: Hispanics n=26 (20%); African-Americans n=8 (6%); Asian Americans n=3 (2%); and Native Americans n=3 (2%). These groups however were combined into one 'Ethnic' group for the purpose of analyses.

Separate analyses of ethnic differences in the prevalence of schizophrenic type disorders (schizophrenia or schizoaffective) with comorbid substance use disorders versus other Axis I disorders with comorbid substance use disorder were conducted. Schizophrenic type disorders were present in 75.0% of White comorbid groups (n=69) and 77.5% of Ethnic comorbid groups (n=31) (p=0.76). No statistical differences were present showing equivalent prevalence's between the two groups. Additional analyses on ethnic differences in the whole sample (age, gender, drug severity, service use, functioning and treatment arm outcomes) were conducted. However these analyses were not performed separately for the schizophrenia type comorbid group.

A UK study by Cantwell et al. (1999) looked at the prevalence and pattern of substance use and misuse in first-episode psychosis. Between 1992 and 1994 all patients aged between 16-64 presenting to secondary care services for the first time with psychotic symptoms were examined. Patients who met criteria for substance withdrawal or intoxication states

were excluded. In total 168 patients were included in the study. Data on substance use and misuse were collected using a combination of the Schedules for Clinical Assessment in Neuropsychiatry (SCAN) (or where an interview with the patient was not possible the Item Group Checklist), and the Personal and Psychiatric History Schedule (PPHS)

Substance use was categorised in three ways; any drug use (use of illicit drugs at least once a month in the year before inclusion in the study); any drug misuse (daily use for a period of at least 2 weeks in the same year); and alcohol misuse (daily use for a period of at least 2 weeks in the same year associated with evidence of significant psychological, social harm or dependence). An analysis on each drug that was misused was also conducted.

Of 168 patients included in the study only 18 (11.7%) met criteria for alcohol misuse and 30 (19.5%) for drug misuse. Substance related psychosis was reported in 13 patients and 92% of those patients were White (n=12). The prevalence of comorbid substance use was equivalent in White, African-Caribbean and other ethnic groups (9/29 African-Caribbean users v. 48/125 non-African-Caribbean users). However substance misusers were less likely to be of African-Caribbean ethnicity (2/29 African-Caribbean compared with 40/125 non-African-Caribbean  $\chi^2=7.48$ ,  $P<0.007$ ; OR 0.16, 95% CI 0.02-0.73).

The concern with these findings is that the number of patients in the African-Caribbean group was very small and might be considered too small for valid statistical analysis. The small number of non-White patients in the sample may have been due to the geographical location of the study population (Nottingham).

The findings from this study highlight one of the reasons why smaller studies have tended to collapse ethnic minority groups into one category and compare them to patients native to the study's country. Another point to be considered is that African-Caribbean's were compared to a heterogeneous group of 'non-African-Caribbeans', who do not

necessarily share the same social, cultural or economic experiences. Additionally the findings cannot be compared to studies that examine differences between White (Caucasian) native and African or Caribbean immigrant groups. Cannabis and alcohol were the most commonly misused substances yet Cantwell et al. (1999) note that although use of other substances was not uncommon, misuse as defined by their criteria was rare. Suggesting the possibility of too restrictive criteria which may have led to an under-diagnosis of comorbidity.

A first incidence of psychotic illness study was conducted in The Hague, Netherlands (Selten, Slaets & Kahh, 1997; Selten & Sijben, 1994; Selten, Veen, Feller et al., 2001). All individuals aged between 15 and 54 years old who made contact with a physician for a suspected psychotic illness between April 1997 and April 1999 were included. The aim of the study was to compare the risk of first contact with services for a psychotic disorder between the native Dutch (those who were born and whose parents were born in the Netherlands), and immigrant populations.

Immigrants (both first and second generation) were divided into four ethnic groups: Turkish; Moroccan; Surinamese; and other. The only patients excluded from the study were those who were diagnosed with substance induced psychosis and patients who were illegally resident in The Hague or had been resident there for less than six months. Veen et al. (2002) reported on information collected on substance use as part of the study. Based on definitions used in the earlier UK study by Cantwell et al. (1999) substance use was split into two types; any substance use; and any substance misuse. Cannabis misuse was also analysed separately.

The final study sample consisted of 179 subjects. One hundred and ten (61%) patients were diagnosed with schizophrenic disorders (DSM-IV: 295.x), 21 (12%) with mood disorders with psychotic features (DSM-IV: 296.x4) and 50 (28%) with other nonorganic psychotic disorders (DSM-IV: 297.1, 298.8, 298.9).

The study observed that 23% of Native Dutch (Caucasian) psychosis patients had substance misuse. The lowest prevalence of substance misuse was found in Moroccan patients (17%) and the highest prevalence in the 'Other' ethnic group of patients (33%). Despite this, no significant differences in the prevalence of any substance use, any substance misuse or cannabis misuse were found between immigrants and Dutch national patients. One of the methodological critiques of this study (as with many epidemiological studies in this area), is that substance use and misuse was assessed using verbal information from the patients, key informants and the responsible clinician and not a structured measure of substance misuse which may have led to some measurement bias.

Another study published in 2003 by Copeland et al. (2003) assessed racial differences in the prescription of antipsychotic medication among schizophrenic veterans receiving care through the Department of Veterans Affairs. Outpatient pharmacy records from the National VA Psychoses Registries for a year period (October 1998 to September 1999) were examined.

Patients were included in the study if they had been diagnosed with schizophrenia, if they were given prescriptions for antipsychotic medication as outpatients ( $n=69,787$ ), and if valid data regarding race and age (age  $\geq 18$ ) were available. The diagnosis of schizophrenia was obtained from administrative data for outpatient visits and inpatient stays and patient's race was recorded on the database as "observed" race. The ethnic breakdown for the sample included 5,955 Hispanic patients (8.5%), 21,032 African American patients (30.1%), and 42,800 White patients (61.3%). The category "Hispanic black" (0.6%) was considered too small for separate analyses so was combined with "Hispanic White" (7.9%). Patients were considered to have comorbid diagnosed substance abuse if it was noted in either inpatient or outpatient records on at least two occasions.

The study found that around 27% of the patients had a diagnosis of substance use or dependence during the study period. In line with the Ahuja et al. (2007) study substance use disorders were more common among African American patients (38%) than Hispanic (23%) or White patients (22%) ( $\chi^2=2001.6$ ; d.f.=2,  $p<0.0001$ ). Although it was found that having a comorbid diagnosis of substance abuse increased the likelihood of receiving certain antipsychotics they failed to identify whether these increased likelihoods were the same in different ethnic groups.

A UK based study by Miles et al. (2003) investigated the characteristics of a group of patients with a comorbid psychotic illness and substance use disorder. Data was collected as part of the Comorbidity Dual Diagnosis Study (COMO), a randomized controlled trial of a case manager training intervention focused on knowledge and attitudes about dual diagnosis and on clinical and social outcomes of the case manager's clients.

Thirteen community mental health teams (CMHTs) took part and case managers were randomly allocated to either an experimental group who received training immediately or a control group who received training after 18 months. Patients with an ICD-10 diagnosis (made by psychiatrists and recorded in case notes) of a psychotic disorder as well as a rating of comorbid drug or alcohol abuse or dependence were included in the study (Miles et al., 2003; Afuwape et al., 2006). Screening of all patients was done by case managers using the Clinician Alcohol Use Scale (CAUS) and the Clinician Drug Use Scale (CDUS) and patients who were rated as at least abusing or dependent on at least one substance met the study criteria for dual diagnosis.

Of the 1,560 clients on the caseloads of these case managers, 1,271 had a clinical diagnosis of psychotic illness. Eighteen percent of cases with a psychotic illness ( $n= 233$ ) met the criteria for dual diagnosis. Of those 233 patients only 69% ( $n=160$ ) agreed to be interviewed, however in addition to the CAUS and the CDUS the Alcohol

Use Disorders Identification Test (AUDIT), was completed by case managers for all patients giving detailed information about patterns of substance use.

Categorisation into substance abuse groups was based on 'best available information' for all sources. For those who were interviewed (and admitted substance use) self-reported substance misuse was used whereas case manager recorded substance abuse/dependence was used in all other cases. After sensitivity analysis of case manager and patient reported drug abuse only 213 patients remained in the dual diagnosis sample.

Substance abuse/dependence was categorised into four different groups for the main analyses: Alcohol only; cannabis only; stimulant only; and cannabis and alcohol. Analysis of Variance and Kruskal Wallis test were completed and on significant results post hoc Bonferroni contrasts were used to compare pairs of subgroups. Significant differences were found by ethnicity ( $F=21.228$ ,  $d.f.=3$ ,  $p<0.001$ ;  $n=210$ ). Post hoc tests confirmed that patients in the alcohol-only subgroup were more likely to be White European (White 68%, Black 23%; and other 9%), whereas those in the cannabis-only subgroup were more likely to be 'black' (Black Caribbean, Black African, or Black British) (White 17%, Black 79% and Other 3%). Differences in ethnicity were still significant when the analyses were repeated first with the subgroups based on the case managers' ratings and then with the subgroups based on patients' self-reported substance use.

Despite being one of the first studies in the UK to look at ethnic differences in comorbidity psychosis and substance use disorder populations and more importantly considered to have tight definitions of this type of comorbidity, a few methodological criticisms can be made of this study. For patient self-reported drug comorbidity (namely not alcohol), any reported use in the previous month was considered potentially problematic and used in analysis. The rationale behind this being that persons with severe mental illness may be vulnerable to

adverse effects of even low levels of drug use (Mueser et al., 1992; Drake et al., 2001) (Miles et al., 2003).

Interestingly when they compared patient and case manager reports, the majority of patients remained in the same category when the case manager ratings were used as opposed to the patients' self-reports as the basis of classification (82 % (n=46) in the alcohol-only group; 55% (n=17) in the alcohol and cannabis group; 71% (n=15) in the cannabis-only group; 62% (n=24) in the stimulants-only group; and 77% (n=10) in the other substance group). This suggests low sensitivity and specificity of the CDUS and CAUS scales which were used as a screening tool for inclusion to the study.

As part of the same study Afuwape et al. (2006) looked at the differences in prevalence or dual diagnosis between each of the Black ethnic subgroups and White patients using the ratings from the CAUS and CDUS. Black British patients (23%, n=27) had the highest prevalence alcohol abuse only comorbidity (White, 15%, n=101; Black Caribbean, 5%, n=11; Black African, 14%, n=11), ( $p<0.001$ ). The same pattern was found for prevalence of cannabis abuse only comorbidity ( $p<0.001$ ), (White, n=42 (6%); Black Caribbean, n=15 (7%); Black African, n=12 (10%); Black British, n=46 (40%)), as well as stimulant abuse only comorbidity (White, n=25 (4%); Black Caribbean, n=6 (3%); Black African, n=5 (4%); and Black British, n=13 (11%)).

Afuwape et al. (2006) also examined sociodemographic differences in White and Black subgroups. Black African (mean age=33) and Black British (mean age=32) patients were significantly younger than White (mean age = 40) and Black Caribbean (mean age=43) patients. Black Caribbean patients had the longest mean contact with services with 83% having their first contact with services last more than five years compared with only 36% in the Black African group having been in contact for the same length of time ( $p<0.001$ ). There were no other significant socio-demographic differences between White and any of the Black subgroup patients.

In 2007 Ahuja et al. (2007) reported on a study investigating ethnic differences in the clinical diagnosis of schizophrenic disorders (according to ICD-9) and associated comorbidities among inpatient discharges (n=24,810) in Louisiana hospitals between 2000 and 2003. The Louisiana Hospital Inpatient Discharge Database (LAHIDD) which has data on all inpatient discharges in the catchment area was used.

Each inpatient may have had multiple admissions over the three years, so analysis was divided into two types: number of discharges; and number of patients (unduplicated discharge analysis). Forty-four percent of patients (i.e. unduplicated discharges) with schizophrenic illness had a Black/African American ethnicity compared with 31% who had a White/Caucasian ethnicity (n=10,214).

Data on comorbidities was only available for the 2003 discharges (n=6,848) as the file structure of the database would not allow analyses of more than one year at a time. Primary diagnosis at discharge was recorded along with the possibility for up to eight comorbidities to be recorded as 'other diagnoses'. Incidents of substance (drug) related mental disorders and alcohol related mental disorders according to ICD-9 (drug psychoses, drug dependence, non-dependent abuse of drugs, alcohol psychoses, and alcohol dependence syndrome and alcohol abuse) found in one or more of the eight 'other' diagnoses were selected for analysis.

Of the 6, 848 discharges for with a schizophrenic illness in 2003 Ahuja et al. (2007) found that 54.7% of discharges were from Black (Black or African American) patients compared with 31.9% from White (Caucasian) patients. At patient level (unduplicated discharges) 53.2% of patients with a schizophrenic illness were Black and 34.0% were White (n=3,950). Of all 2003 patients discharged with a schizophrenic illness 1,082 (27.4%) had a comorbid substance related mental disorder recorded as one the eight 'other' diagnoses and 394 (10%) discharges



had an alcohol related mental disorder recorded as a comorbidity in one of the eight 'other' diagnosis.

When the ethnic distribution of discharges and patients with co-occurring substance and alcohol use disorders were examined they found that 64.1% of discharges with substance related comorbidity were from patients with a Black ethnic grouping and 24.8% were from a White ethnic grouping. For those discharges with an alcohol related comorbidity, 63.4% were from a Black ethnic group compared with 23.5% from a White ethnic group (n=6,848). Looking at the ethnic distribution at patient level they found that 63.7% of patients with substance related comorbidity were Black and 27.2% were White. For alcohol related comorbidity, again a similar pattern was found with 64.7% of patients coming from a Black ethnic group and 23.8% of patients coming from a White ethnic group (n=3,950).

As a survey of all inpatient discharges in one geographical area these findings could tell us something about rates of comorbidity in the inpatient population, however as with some of the other studies reviewed here (e.g. Rosenthal et al., 1992; Jerrell & Wilson, 1996 & 1997) no statistical analysis was done to determine whether prevalence of comorbidity within each ethnic group differed. Between group analysis of prevalence of comorbid substance and alcohol related mental disorders is needed to truly ascertain if belonging to a Black ethnic group carries more risk of comorbidity.

Additionally there was a high proportion of missing and inaccurate data which may also have contributed to selection bias. The authors acknowledge that data on ethnicity was in some instances poor. Data on cases where hospitals did not follow up to determine patient ethnicity and left the discharge record blank were coded as missing and individual patients were sometimes coded as being from two different ethnic groups in different discharge summaries (532 cases had their race changed).

Unlike many epidemiological studies in this area, drug or alcohol induced psychoses was not excluded. There are many clinical differences between organic or substance induced psychosis and non-organic psychotic disorders. Substance induced psychosis by definition is a secondary psychotic disorder to substance intoxication and does not share the same clinical characteristics, illness course or outcomes as comorbid psychosis and substance use disorders (Caton et al., 2005).

A more recent study (McLean et al., 2012), explored clinical phenotypes contrasted demographic and clinical correlates in trans-ethnic schizophrenia populations from Australia, India and Sarawak, Malaysia. The study conducted by The Genetics Research group at the Queensland Centre for Mental Health Research (QCMHR) recruited three cohorts of individuals with psychosis for genetic analyses. McLean et al. (2012) studied demographic and clinical characteristics of schizophrenia in three ethnic groups: Caucasian Australians (n=821); Tamil Brahmin and proximal caste groups from Tamil Nadu, India (n=520); and Iban of Sarawak, Malaysia (n=298). McLean et al. (2012) proposed cultural explanations for any differences in prevalence or characteristic of schizophrenia.

Inclusion criteria were consistent for all three sites: all probands and relatives who had a DSM-IV (APA, 1994) diagnosis of schizophrenia or schizoaffective disorder. For the Australian site and the Sarawak site ethnicity was self-reported (Caucasian and Iban respectively). Patients were considered eligible for inclusion at the Indian site if they were a member of the Brahmin caste from Tamil, Kerala, Karnataka, or Andhra Pradesh, or a member of a geographically proximal caste groups from Tamil Nadu (Mudaliars, Chettiars and Dalits). In addition ethnicity was confirmed through genetic analysis across all three samples.

Despite the Sarawak sample being based on treated rates of schizophrenia, and the Australian and Indian samples being opportunistically recruited, the similarities in the recruitment methods across all three sites still made comparison of these groups valuable.

Trained clinicians used the semi-structured DIGS (Nurnberger et al., 1994) to obtain relevant information about the diagnosis of psychotic, mood, and substance-use disorders in accordance with DSM-IV criteria. Comorbidity was grouped in three ways: Lifetime DSM-IV alcohol abuse or dependence, lifetime DSM-IV cannabis abuse or dependence, and lifetime DSM-IV other drug abuse or dependence.

The study found significant site differences for alcohol, cannabis, and other drug abuse/dependence after controlling for sex. A lifetime diagnosis of alcohol abuse/dependence was found in 40.7% (n=333) of Australian patients compared with 0.8% (n=3) in Indian patients and 10.5% (n=28) in Sarawak patients ( $\chi^2=265.53$ ; d.f.=2,  $p<0.0001$ ). For patients with a lifetime diagnosis of cannabis abuse/dependence a similar trend was found ( $\chi^2=397.06$ ; d.f.=2,  $p<0.0001$ ): Australia (n=372, 45.5%); India (n=0, 0%); and Sarawak (n=2, 0.8%). Additionally analyses were performed comparing those with a lifetime diagnosis of other drug abuse/dependence. Again Australian patients (n=216, 26.5%) had the highest prevalence ( $\chi^2=185.94$ ; d.f.=2,  $p<0.0001$ ), followed by patients from Sarawak (n=0, 0%) and Indian patients (n=7, 2.6%).

It is noteworthy that the authors suggest possible explanations for these differences in the samples. Firstly, they suggest that the small rates of alcohol and drug use in the Indian sample may well be explained by the socio-cultural practices of schizophrenic population, with psychosis patients continuing to live with family members, thus limiting their access to illicit substances. Secondly McLean et al. (2012) argue that Caste may also play a role in this finding. It has been reported that there is a disinclination in the Tamil Brahmin community to use substances such as alcohol, although cannabis use has been noted (Sharma, 1996). Thirdly, a critique of this large study can be made on grounds of selection bias. McLean et al. (2009) state that there were high rates of patients recruited from hostels in the Australian sample which also may go toward explaining high rates of substance abuse and dependence in that sample compared with the Indian and Sarawak samples.

### **3.3.2 Ethnicity as a risk factor for comorbid substance use**

The UK Cantwell et al. study (1999) found that while non Afro-Caribbean ethnicity was not a risk factor for comorbid substance use it was a risk factor (alongside younger age and male gender) for comorbid substance misuse ( $\chi^2=31.632$ , 3 d.f.,  $p < 0.0001$ ) (Cantwell et, 1999).

In a Swedish study of all patients seen at a psychiatric clinic (either as in- or out-patient,  $n=87$ ) between January 1 and May 31 1998, Cantor-Graae et al. (2001) found that non-Swedish ethnicity (defined as patients who were born outside of Sweden or who had at least one parent born outside of Sweden first- or second-generation immigrant), was associated with a life time history of substance abuse ( $p < 0.05$ ). They do note however that although non-Swedish ethnicity was a potential risk factor, the implications of these findings are difficult to interpret in such an ethnically diverse sample.

The Veen et al. (2002) study found that, after controlling for age and sex, the odds for having comorbid substance misuse for Moroccan patients was less than half the odds of Dutch nationals. Equally 'Other' ethnicity was nearly twice as likely as Dutch nationals to have substance misuse. However confidence intervals were fairly wide and overall ethnic differences in odds of for having substance misuse did not reach statistical significance (Moroccans OR 0.4 CI=0.1–1.2; Surinamese OR 1.2, CI=0.4–3.6; Turkish OR 0.8, CI=0.2–3.7; Others OR 1.8, CI=0.7–4.8). They found a similar finding for cannabis misuse however the results were not presented in the paper.

The Comorbidity Dual Diagnosis Study (Miles et al., 2003; Afuwape et al., 2006) investigated whether certain Black ethnicity sub-groups had a greater or lesser risk of having comorbidity (Afuwape et al., 2003). Despite the higher prevalence of cannabis use among Black British

patients the risk for having comorbid abuse or dependence in this group (OR=1.3) was relatively close to that in the White group (OR=1).

### **3.3.3 Ethnic differences in choice of drug**

Afuwape et al. (2006) as part of the UK COMO study (Miles et al., 2003; Afuwape et al., 2006), also examined ethnic differences in primary drug of abuse. The study found that patients from Black British groups were significantly more likely to be rated as abusing cannabis compared to patients from White groups (OR=4.8, 95% CI=2.9-8.1). Black African patients were significantly more likely to be rated as abusing 'other substances' (including hallucinogens, amphetamines, opiates, illicit benzodiazepines and khat) (OR=2.9, CI=1.2-7.2). Black Caribbean patients were significantly less likely to have a comorbid alcohol diagnosis than patients from White groups. (OR=0.3, CI=0.1-0.5). No other significant differences between White and Black groups with regard to case managers' ratings of co-occurring substance abuse was found.

### **3.3.4 Ethnic differences in psychiatric diagnosis and symptom severity of patients with comorbidity**

Previous research has shown that Black patients are more likely to be diagnosed with schizophrenia (Strakowski et al., 1993; Neighbors et al., 1989; Jones & Gray, 1986; Marquez et al., 1985; Lawson et al., 1991; Mukherjee et al., 1983; Adebimp, 1981; Lawson, 1986) and less likely to be diagnosed with an affective disorder (Baker & Bell, 1999). Ethnic differences in mental health diagnosis in comorbid populations is under-reported and the studies in this review that did report it yielded conflicting results.

Jerrell and Wilson (1996 & 1997) in their clinical trial examining the relative cost effectiveness of three specialized interventions for dual

disorders (see above) found no significant difference in psychiatric diagnosis between White and ethnic groups ( $p=0.76$ ). However the sample size of ethnic minorities was fairly small ( $n=40$ ).

However, one of the key authors in comorbid mental health and substance use disorders reporting on findings from a study conducted by the New Hampshire study group (Mueser et al., 2001) found patterns of psychiatric diagnosis between ethnic groups of comorbid patients similar to those in the general psychiatric population. The study examined differences between two cohorts of patients (New Hampshire and Connecticut) with dual disorders who were recruited using similar eligibility criteria and assessed with the same measures with a dual diagnosis (Psychiatric and substance-use diagnoses were based on the SCID).

In New Hampshire, 225 psychiatric outpatients were recruited into the New Hampshire study between 1989 and 1991. In Connecticut, 199 outpatients were recruited into the Connecticut study between 1993 and 1998. Patients were eligible for inclusion in both study sites if they had a DSM-III-R diagnosis of schizophrenia, schizoaffective disorder, or bipolar disorder (New Hampshire  $n=225$ ; Connecticut  $n=166$ ).

Data on comorbid substance use disorders were collected and defined as 'substance (alcohol or drug) abuse or dependence diagnosis within the past six months according to DSM-III-R or DSM-IV criteria (excluding nicotine and caffeine). Several measures of substance abuse (Addiction Severity Index (McLellan et al., 1992); Alcohol Use Scale and the Drug Use Scale (Drake et al., 1990; Mueser et al., 1995); and the Substance Abuse Treatment Scale (McHugo et al., 1995), were used to evaluate both the types and amounts of substances used.

Analyses on the ethnic distribution of patients could only be done using the Connecticut sample due to underrepresentation of minority groups in the New Hampshire sample. A sub-sample of 108 African American patients was compared to sub-sample of 53 White patients.

African American dual diagnosis patients were less likely to be diagnosed with bipolar disorder and more likely to be diagnosed with schizophrenia ( $p < 0.01$ ) compared with White patients (Mueser et al., 2001).

Only a few of the studies examined ethnic differences in symptomatology. The Jerrell and Wilson (1996 & 1997) studies, found ethnic minority clients self-reported slightly more psychiatric symptoms but this difference did not achieve statistical significance. There were no differences in alcohol/drug abuse severity.

The Afuwape et al. (2006) paper reporting on findings of the UK COMO study found that Black British (82%) and Black Caribbean (84%) groups had a significantly higher prevalence ( $p=0.02$ ) of schizophrenia diagnoses in the comorbid sample than in the White (69%) or Black African groups (55%) but numbers with diagnoses other than schizophrenia were too small for meaningful comparisons. Black Africans tended to be perceived by clinical staff as suffering from more severe and persistent symptomatology and impaired psychosocial functioning. However no significant differences in symptom severity by ethnic group were found (Afuwape et al., 2006)

### **3.3.5 Ethnic differences in treatment outcome**

Data on ethnic differences in clinical or psychosocial outcome in comorbid populations was limited. The Jerrell and Wilson (1996 & 1997) studies which examined ethnic differences in outcomes of three treatments for dual diagnosis found that the overall outcomes (including change in functioning and symptom severity scores) of ethnic clients were equivalent to those of White clients at 6 months. The individual treatment groups were significantly different on five outcomes, but only two (substance use symptoms and costs) of those five were ethnic group differences. Drug and alcohol symptoms were lower in the Behavioural Skills group especially for ethnic clients ( $p=0.03$ ). The reduction in

intensive mental health service costs (for acute and sub-acute services) was greater in the 12-Step group, especially for ethnic clients ( $p=0.01$ ) (Jerrell & Wilson, 1996 & 1997).

### **3.3.6 Ethnic differences in experiences of services**

As part of the UK COMO study, Afuwape et al. (2006) found differences by ethnic group for hospital admissions in the 18 months prior to admission with more comorbid Black African patients having been admitted at least once. However, when adjusted for age, this just failed to reach statistical significance. In their study comorbid Black British patients had the longest time in hospital (mean days over 18 month period=105) and were more likely to be detained under the Mental Health Act during the past 18 months ( $p=0.03$ ). Black Caribbean patients had smallest number of admissions ( $p=0.30$ ). Despite the marked ethnic differences in experience of services they found no significant difference between ethnic groups on their satisfaction with services (Afuwape et al., 2006).

One study found that there were no significant ethnic differences ( $p= 0.34$ ) in service use history in the year prior to study entry (number of days in 24-hour care both acute and sub-acute) (Jerrell & Wilson, 1996 & 1997). However anecdotal evidence from the study showed that young African Americans were noted (by clinical staff) to be difficult to place in temporary accommodation during the study because of a combination of fear of increased risk of violent behaviour and culturally inappropriate/unprepared shelters. 12 step recovery programs not participating in the study were also seen as inaccessible to this client group because the majority of them were not culturally sensitive. They also found that ethnic clients received less supportive treatment services during the first 6 months of the intervention program.



A qualitative study by Warfa et al. (2006) interviewed nine dually diagnosed young men aged between 18-35 from a range of local voluntary agencies and statutory services in East London. Broadly, the study aimed at exploring service user perceptions of service effectiveness within three different ethnic groups with comorbid mental health and substance use problems (White British; Black African; and African Caribbean). It also aimed to identify the role culture and ethnicity play in the treatment of service users with comorbidity, uncover perceptions about the adequacy of services and identify gaps in the training needs of social and mental health professionals working with dually diagnosed patients from service user perspectives.

Diagnoses (which were self-reported) and symptoms varied across ethnic groups. Patient histories were generally characterized by frequent hospitalisation, separation from family, education problems. The participants reported varying degrees of service effectiveness and they tended to measure this through the services ability to address social and cultural needs. Migration related stress emerged as a common theme and was in one case explained in terms of their onset of symptoms.

The study found that mental health issues were addressed more thoroughly than substance abuse issues. Some participants mentioned that they used support services which were often culturally specific and felt that mental health services would be improved if they became more culturally aware. Additional services utilised included Somali support services, Ethiopian community centres and spiritual services which were accessible during their hospital stay. For those participants who used counselling services or alternative spiritual or cultural support services, these services or groups were seen as being an integral part of their healthcare.

All of the subjects in this study received pharmacological treatment for their dual diagnosis, with the majority having been hospitalized. The majority of participants reported that they were encouraged by their healthcare providers to stop using drugs or alcohol; however they rarely

reported specific advice or a specific intervention to deal with their abuse (Warfa et al., 2006).

### **3.4 CONCEPTUAL ISSUES/METHODOLOGICAL ISSUES**

If we are to interpret the findings above it is important to outline some of the conceptual and methodological issues associated with research in this area.

#### **3.4.1 Differences in study population and difficulties in measuring differences in small samples**

It can be argued that many studies in mental health sometimes fail to recruit large enough numbers of comorbid patients to either make accurate generalisations or to obtain statistical significance. Three of the studies (Cantwell et al., 1999; Strakowski et al., 1992; Afuwape et al., 2006) that reported ethnic differences in the prevalence of comorbidity had what might be considered small sample sizes meaning either statistical significance was not achieved or if it was the findings should be interpreted with caution. There is also the problem of performing analyses on sub groups (for example women or young people) of these small comorbid samples.

Furthermore the population sample from which several of the studies drew their exposed sample from differed considerably. Three of the studies were conducted in services for dually diagnosed patients and two were conducted within the general population. Even though the remaining studies were conducted among psychotic populations, there a marked differences within this group. Six studies investigated psychotic populations, two of which examined first-episode psychosis while five studies looked at patients with schizophrenia. Comparing evidence on prevalence, characteristics and outcomes of 'comorbid' patients between

studies where there is no standard group of interest is difficult, especially when there are clear differences between these diagnostic groups even without comorbid substance use.

Most of the samples in the above studies have a higher proportion of male patients. The Jerrell and Wilson study did manage to highlight some of the more complex challenges in treating female dually diagnosed patients, as well as patients from younger age groups. Nevertheless, prevalence and outcome measures for these sub-groups within White and non-White populations and treatment samples are under-researched.

Warfa et al. (2006) was the only qualitative study. It stands to reason that studies like these are never going to measure prevalence rates but despite this the sample was very low and the authors acknowledge that the nine patients may not be representative of the three ethnic groups. The study also focused on the experiences of male patients, again overlooking the interaction gender may have on treatment experiences

### **3.4.2 Conceptualising and measuring ethnicity**

The Warfa et al. (2006) study was the only study to look at some of the more complex cultural issues associated with ethnicity and its impact on or interaction with treatment outcomes. This is in contrast to studies which have chosen to focus on differences based on nationality (Veen et al., 2002), ignoring any likely cultural differences between, for example, first and second generation patients.

Although their analysis of the interaction between ethnicity and treatment outcomes was not limited to a simplistic 'White group' vs. 'homogeneous ethnic group' comparison as the Jerrell and Wilson study (1996 & 1997) was, Veen et al.'s (2002) conceptualisation of ethnicity was based mainly on immigration (Dutch nationals vs. Dutch

immigrants). Operationalising ethnicity this way fails to illuminate some of the more complex elements to race and ethnicity as well as any similarities second or even third generation immigrant groups may have had with Dutch nationals in terms of identity, cultural values and attitudes.

The Ahuja et al. (2007) study is another example of the problem of not using standardised categorisation of ethnicity. In this study the 'Black' group consisted of 'Black' and 'African American'. The term 'Black' was not unpacked or scrutinized; it may well have been that patients who were observed to have dark skin were categorised as 'Black' and included with patients that self-defined as African American. The problem with this is that 'Black' is a heterogeneous group and may have included Native Africans, Caribbean's, dark skinned middle easterners as well as patients of mixed heritage. Additionally Carra et al. (2009) highlight the need to disaggregate 'Black' ethnic groups within comorbidity research, particularly as British born Black patients tend to have much higher prevalence's of comorbid substance abuse.

In most of the studies measures of ethnicity were far from sensitive, sometimes using the crude 'Black' category for non-White clients. The paper by Afuwape et al. (2006) which examined ethnic differences in a sample of dual diagnosis patients from the COMO study did manage to highlight some of the differences within Black patient groups (Black African, Black Caribbean and Black British) despite not obtaining significance on many of the relationship tests.

One criticism though is that during their screening process any patient that was of mixed parentage (i.e. one parent was Black and the other parent was White) who identified themselves as Black was put in the Black British Category. They do not detail the percentage of mixed parentage patients in this category or where they placed mixed parentage patients that did not identify themselves as Black. With increasing numbers of children from mixed parentage backgrounds it is important to make a distinction between this subgroup and Black and

White groups, even when patients align themselves with one particular group.

The Copeland et al. (2003) study also illustrates how defining ethnicity can be problematic. Firstly ethnicity was ascertained by the 'observed' race of the patient by the clinicians that saw them when they were treated in either inpatient or outpatients. As Singh (1997) notes 'Measures of ethnicity based simply on physical appearance highlight the racial foundation of the ethnic façade' and can lead to observer bias (Singh, 1997, p. 306). Singh (1997) argues that adding measure such as place of birth or place of parental birth can help narrow definitions of ethnic groups, but even this may not necessarily produce homogeneous samples. Self-assigned ethnicity has become a popular measure in psychiatric epidemiology since it appears to eliminate observer bias (Singh, 1997).

Secondly the Copeland et al. (2003) study combined the 'Hispanic Black' and Hispanic White' group into one ethnic category (because of small numbers) to compare to White and African American patients. While this may capture the differences in the shared culture of Native Americans, versus African Americans versus Hispanics it fails to recognise the potential socio-economic differences that Black skinned Hispanics may have from White skinned Hispanics.

Although there are notable selection biases in the McLean et al. (2012) study, measurement of ethnicity was determined through genetic analyses. These findings may be better understood in terms of race rather than ethnicity and as genetics does not determine cultural groupings or identity questions as to the validity of these findings may still remain.

### **3.4.3 Conceptualising and measuring comorbidity**

It is important that studies exploring comorbidity of psychosis and substance use disorders are homogeneous in their conceptualisation. Studies need to distinguish between co-occurring substance use and the dual diagnosis of misuse, abuse or dependence (see Table 3). Differentiating between the negative effects of co-occurring substance 'use' as opposed to a diagnosable substance use disorder is an important consideration for studies looking at the outcomes of dually diagnosed patients. Studies that have looked at the dose-response effect of cannabis use in psychotic populations have found that heavier cannabis use is more strongly associated with psychotic relapse (Linszen et al., 1994).

The majority of studies defined comorbidity as diagnosable substance abuse or dependence (the main differences between the two are dependence is additionally characterised by symptoms of withdrawal and increased tolerance). However definitions ranged between studies. Even when diagnostic criteria were employed it is difficult to compare findings which look at differing degrees of severity of comorbid substance use.

Miles et al. (2003) argued that their low threshold for self-reported (as opposed to case manager rated which made up a significant proportion of the eligible sample) drug 'abuse' was based on the observation that persons with severe mental illness may be vulnerable to adverse effects from even low levels of drug use (Drake, Essock & Shaner, 2001). Studies using differing concepts of comorbidity make comparison difficult. In some studies there were inconsistencies within the study. Although many studies may be fairly consistent in their measurement of comorbidity the Copeland et al. (2003) paper highlights the problems in interpreting findings when terms with different clinical meaning are used interchangeably.

Most studies used ICD or DSM criteria to define comorbidity. The difficulty is that not all studies used the same information sources to determine diagnoses. For example, some studies used case notes while other used structured clinical/research instruments to collect information on psychopathology to which they applied the diagnostic criteria. One of the studies used self-reported (Warfa et al., 2009) substance use disorder as the only measure, which may or may not have pertained to a clinical diagnosis and may not be comparable to studies which used both validated/structured diagnostic schedules and formal diagnostic criteria.

Rosenthal et al. (1992) note in their paper that data for the three studies were collected differently. They argue that the data in study I which was collected using case note review (albeit from routine clinical diagnoses), were likely to be 'methodologically under sensitive in documenting and diagnosing multiple substance abuse disorders' (Rosenthal et al., 1992, p. 18). Data for Study III derived from standardised structured clinical interviews. When they compared the rate of poly-substance use in Study II (where data was collected using routine clinical assessment) with that of Study III they found a five times increase in study III. They propose that this is mostly likely because standardised assessment provides a much more comprehensive assessment of multiple substance use routine clinical assessments, 'When routine clinical procedures take account of substance abuse, they may focus only upon the one or two addictive disorders with the most obvious implications for treatment' (Rosenthal et al., 1992, p. 18).

The discussion section of the paper by McLean et al. (2012) highlights a methodological issue that cuts across issues of ethnicity measurement as well as psychopathology measurement. They note that caution should be made when using standardised/structured psychopathology instruments across different cultures, as converting thoughts and feelings across languages can be difficult (Barrett, 2004). McLean et al. (2012) employed rigorous translation methods on their instruments (DIGS) and used local interviewers who interviewed in the country's native tongue. Additionally they tested the inter-rater reliability

(within and between sites) of the DIGS. However they do admit that this method was not performed for other measures used in the study and inter-rater reliability tests were not performed for diagnosis between India and Sarawak.

The problem of reliability and validity of data collection tools is not the only issue for concern when measuring comorbidity or more specifically substance use disorders. The employment of diagnostic criteria (ICD and DSM) adds an important layer of accuracy in measurement and comparability of substance use disorders within and between epidemiological studies. However the validity and reliability of these diagnostic criteria has been challenged (Rounsaville, 2002). Ratings can span across several domains. Similar to the Cantwell et al.'s (1999) study, Veen et al. (2002) used the SCAN and PPHS study instruments as well as consensus ICD-10 diagnostic criteria, despite this 'use' and 'misuse' were defined by frequency and duration of substance use alone and did not seem to include some of the criteria's based on psychological, social or legal consequences of substance use.

Misuse, abuse and dependence can be measured on various dimensions such as symptoms of withdrawal; effect use has on social relationships or interactions; or whether the patient has had any involvement with the criminal justice system because of illicit drugs or alcohol.



**Table 3: Comparison of Definitions of Comorbid Substance Use**

<b>Authors</b>	<b>Use</b>	<b>Misuse</b>	<b>Abuse</b>	<b>Dependence</b>	<b>Other*</b>
<b>U.K</b>					
Cantwell et al. (1999)	✓	✓			
Miles et al. (2003) and Afuwape et al. (2006)			✓	✓	✓
Warfa et al. (2006)					✓
<b>USA</b>					
Strakowski et al. (1992)			✓		
Rosenthal et al. (1992)			✓	✓	✓
Jerrell and Wilson (1996 & 1997)			✓	✓	
Mueser et al. (2001)					
Copeland et al. (2003)	✓			✓	
Ahuja et al. (2007)			✓	✓	✓
<b>Other</b>					
Cantor-Graae et al. (2001) (Sweden)			✓		
Veen et al. (2002) (Netherlands)	✓	✓			
McLean et al. (2012) (Australia, India and Sarawak)			✓	✓	

\*Substance use disorder; dependence with institutionalisation; drug psychosis

In addition, the time-line of the diagnosis in which substance misuse and mental health problems are 'actively comorbid' is an issue. As noted by Todd et al., (2004) comorbidity can occur with substance misuse as the primary disorder or as an underlying disorder. The lack of explicitly defining the dual diagnosis time-frame or comparing studies with different time frames could help to explain disparities in prevalence figures across studies (Todd et al., 2004).

Many, but not all of the studies excluded patients with substance induced psychosis. It has been shown that this particular group are distinct in terms of demographic and clinical outcomes to patients who have a primary psychotic disorders and co-occurring substance misuse (Caton et al., 2005). As Schuckit (2006) notes, the methods of operationalising diagnostic criteria and definitions of comorbidity or dual diagnosis determine the results of studies examining the phenomenon.

### **3.5 CONCLUSIONS**

The evidence presented so far pertaining to an interaction between ethnicity and comorbid diagnosis is a 'mixed bag' to say the least, and seems anecdotal in comparison to the corpus of epidemiological literature around ethnicity and psychosis or ethnicity and substance abuse/dependence. It is unclear whether ethnicity can be considered a risk factor for comorbid substance use or not, and if it is whether Black Caribbean (or other ethnic groups) would be at greater risk.

Several studies have found ethnic differences in the prevalence of comorbidity. However, issues with sample size, measurement and operationalisation of concepts need to be weighed against these findings. There does seem to be some evidence that Black groups tend to have higher prevalence of comorbid substance abuse/dependence in

psychiatric populations. We are yet to see if this trend however holds up in drug abusing populations. When comparing prevalence rates between these two treatment settings in the US the evidence does suggest that there is a bias towards White clients in the mental health setting and Black clients in the drug abuse treatment setting. It is still to be determined if this is the same in UK.

Findings from the British Crime Survey 2001/2002 (BCS) have shown that people from Black Caribbean groups are more likely to use cannabis than White or Black African groups (Aust & Smith, 2003). Evidence from the studies outlined here seem to refute this showing cannabis use is equivalent between these groups and that it is cocaine use which tends to be higher in Black comorbid populations.

In line with evidence of higher levels of compulsory admission within Black patients in the psychotic population (Morgan et al., 2004), the evidence presented here points towards a similar pattern in comorbid populations (Afuwape et al., 2006).

Half of the studies reviewed here were conducted in the US. Only four studies were conducted in the UK highlighting the need for more research in this area here at home. Research into possible interactions between comorbidity, ethnicity and other socio-demographic characteristics (such as gender and class), not to mention ethnic differences in treatment outcome will also be necessary.

More qualitative research similar to the Warfa et al. (2006) study will help illuminate important issues such as immigration, differences in drug choice between first and second generation Black and Asian ethnic groups and engagement with services that are missing from population and cohort studies and may in fact be more salient in the British treatment setting.

### Chapter Summary 3.

#### **Chapter Summary**

##### Aims of the Chapter:

To present findings from a systematic review of current literature on ethnicity and comorbidity with particular attention given to ethnic differences in prevalence and ethnicity as a risk factor for comorbid diagnosis.

##### Key Points:

- Evidence relating to the relationship between ethnicity and prevalence or risk for comorbidity is disparate
- There is evidence that minority groups with comorbidity may be at higher risk for certain negative outcomes
- More UK based epidemiological and qualitative research is needed to in this area.

## **CHAPTER 4: MEANING IN EXPERIENCE: HELP SEEKING AND CONSTRUCTIONS OF MENTAL ILLNESS, SUBSTANCE USE AND SERVICE USE EXPERIENCES IN PSYCHOTIC AND SUBSTANCE USE DISORDER POPULATIONS**

### **4.1 INTRODUCTION**

An overview of evidence detailing the relationship between comorbid psychosis and substance use disorders and poor clinical and social outcome, as well as the relationship between Black Caribbean ethnicity and negative outcomes in psychotic populations and substance abusing populations, has been discussed in Chapter 2. Ethnic differences in the prevalence of comorbidity, service utilisation and clinical and social outcomes of patients with comorbidity has also been discussed in the previous section.

Much of this research is epidemiological, and although this helps to highlight patterns in clinical and social characteristics and service utilisation of those with comorbidity it does not claim to explain why those patterns may be present. Furthermore, research in this area has been conducted almost exclusively within psychiatric and psychological research communities with the arguably understandable aims of enumerating rates and patterns of referral, admission and clinical and social outcome.

In line with realist approaches to scientific enquiry (a notion that I will discuss in more detail in Chapter 5), epidemiological data from this type of research has been used to test hypotheses relating to, and correlations between, the outcomes of interest as well as socio-

demographic and clinical characteristics (Morgan et al., 2004). Skrabanek (1994) has argued that historically much of epidemiological research has been subject to the 'black box' strategy, whereby the causal mechanism behind an observed relationship remains hidden and unknown, despite the assumption of a causal link by virtue of a statistically significant association. Black Caribbean ethnicity may well be associated with poor clinical or social outcome in people with psychosis or increased likelihood of certain types of substance use in the general population, yet the mechanism or causal link that lies behind these associations remains a mystery.

Using statistical analyses to uncover associations between disease and exposure may tell us if there are ethnic differences in the risk of having comorbidity. However, they may not help explain the reason for this association. For example, people from Black Caribbean ethnic groups may find heavy cannabis use more socially acceptable which, in conjunction with socio-economic pressures, puts them at greater risk of having a psychotic disorder. Alternatively, conceptualisations of mental illness in Black Caribbean populations may lead to a delay in seeking help for psychosis and an increased need to self-medicate with illicit drugs and/or alcohol.

## **4.2 EXPLAINING ETHNIC DIFFERENCES IN PSYCHOTIC AND SUBSTANCE ABUSING POPULATIONS**

If we are going to understand associations between ethnicity and prevalence and correlates of comorbidity we need to understand why psychotic patients from different ethnic groups use drugs and alcohol. We also need to examine whether ethnic differences in substance use behaviours after initial episodes of illness may impact on illness outcome and patterns of service utilisation.

Several questions need to be considered when looking at epidemiological research in this area: What is the direction of the causal link between substance use disorder and psychosis?; Are there differences in the conceptualisation of mental illness, substance use and help-seeking between Black and White ethnic groups and are these differences likely to explain ethnic differences in prevalence of comorbidity or relapse and compulsory admission rate?

For example research highlighting the relationship between ethnicity and compulsory admission in psychotic populations has also looked at the role of poor insight suggesting that poor insight may be an indicator of a worse clinical presentation. Moodley and Perkins, (1991) found in a small study of pathways to care in London, found that 32% of Black Caribbeans did not believe they had a problem compared to none of the Whites. Moreover other work has shown that Black patients tended to deny mental illness (Pipe et al., 1991; Commander et al., 1999). Morgan et al. (2004) argued that it is difficult to determine whether denial of mental illness is a function of the underlying illness or a reflection of different explanatory models of health or illness belief used by minority ethnic groups.

In addition higher rates of compulsory admission in Black Caribbean patients could be explained by differences in how Caribbean and White families respond to mental illness. Speculating on the work of Harrison et al. (1989), Morgan et al. (2004) suggest that more severe stigmatisation of mental illness in the Black Caribbean community may hinder voluntary help-seeking.

Suggestions for working with drug abusers published by the National Treatment Agency for Substance Misuse suggest that drug use among black and minority ethnic users should be located within a wider context of social exclusion, deprivation and discrimination (Models of Care, 2003). There is some research evidence that black and minority ethnic drug users find treatment services less accessible than do the rest of the population and are under-represented in treatment services

(Advisory Council on the Misuse of Drugs 1998; Mirza et al., 1991; Patel 1993; Sangster et al., 2002).

Institutional racism has also been suggested as an argument for higher incidence of schizophrenic illness (Fearon et al., 2006), more compulsory admission (Morgan et al., 2005) and negative experiences of mental health and drug treatment services (Perera et al., 1993; Khan, 1999).

To understand why certain ethnic groups may be more likely to have certain experiences we need to draw on academic realms (in addition to Psychiatry and Psychology) within the Social Sciences: Sociology and Anthropology. Research in these areas, which has tended to be qualitative in nature, may help uncover the meaning behind the behaviours of those with psychosis (Salmon, 2000) and comorbid psychosis and substance use disorders.

Constructions and beliefs about health are key to understanding these relationships: the way in which people construct illness, but also the way they construct substance use and help seeking, may help uncover the relationships between ethnicity, psychosis, substance use, poor illness outcomes and negative service use experiences. Moreover, beliefs about causes of illness and drug use initiation are likely to be at the heart of constructions of comorbidity.

It is beyond the scope of this thesis to discuss all the literature around models of health belief and help-seeking, however this chapter does aim to give an overview of the key literature in relation to illness, substance use and treatment experiences of patients with psychotic disorders and substance use disorders.

A discussion of the limitations of applying these models and frameworks to comorbid populations, discussion of lay belief frameworks in Black ethnic cultures, theoretical hypotheses of the relationship between psychosis and substance use disorders, as well as a discussion



of other qualitative research that has helped uncover beliefs and experiences of patients with comorbidity both generally and within specific cultures is also attempted.

### **4.3 MODELS OF HELP SEEKING AND HEALTH BELIEF**

Theoretical models of beliefs about illness that are shared by the same ethnic and cultural groups which may help us interpret why, when and how people seek help have received much attention in the last ten years (Morgan et al., 2004). Rüdell, Bhui & Priebe, (2009) have argued that two types of theory around illness perception research have dominated: (a) Explanatory Models; and (b) Illness Representations as a part of the self-regulatory theory. These theories will be briefly outlined and discussed in relation to ethnicity and help-seeking.

#### **4.3.1 Illness behaviour and help-seeking**

In order to understand constructions of illness experience we must first draw a distinction between a disease or illness itself and the behaviours associated with that illness. For Kleinman (1986), illness behaviour is simply the way researchers within sociology have conceptualised illness. What underlies the distinction between these two concepts is that disease (a biological or psychological process) is transformed into illness (a psychosocial process) or illness behaviour through a socio-cultural process that shapes how an individual and significant others perceive, and respond to, symptoms of the disease (Morgan et al., 2004).

Early research by Mechanic (1968) identified ten factors known to influence illness behaviour. These factors relate to the symptoms of a disease that a person is experiencing (see Figure 4).

**Figure 4: Ten factors known to influence illness behaviour.**

<b>Factors influencing illness behaviour</b>
1. Visibility, recognisability, and perceptual salience of deviant signs and symptoms
2. The extent to which the symptoms are perceived as serious
3. The extent to which symptoms disrupt family, work and other activities
4. The frequency of appearance of the deviant signs or symptoms, their persistence, or their frequency of recurrence
5. The tolerance threshold of those who are exposed to and evaluate the deviant signs and symptoms
6. Available information, knowledge and cultural assumptions and understandings of the evaluator
7. Basic needs which lead to autistic psychological processes
8. Needs competing with illness responses
9. Competing possible interpretations that can be assigned to the symptoms once they are recognised
10. Availability of treatment resources

Adapted from Mechanic, 1968, pp. 142-155.

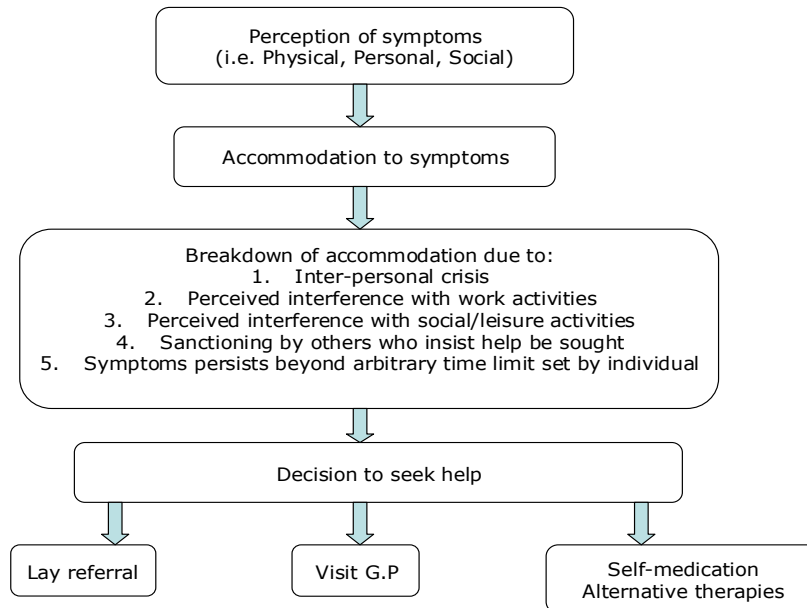
Although, as Mechanic (1968) acknowledged, this list is not exhaustive, we can see how these factors all relate to the experience and effect of symptomatology for the person as well as his/her surrounding support network, the cultural beliefs about illness that are held, the response that the individual and their support networks have to the symptoms and the type of available treatment options.

In other words, as Morgan et al. (2004) noted, these factors highlight how responses to illness or illness behaviours are a combination of 'self' and significant 'other' -orientated illness conceptualisations and roles. In addition, Morgan et al. (2004) highlight how Mechanic (1968) stressed the need for research to distinguish between self-defined and other-defined illness, a distinction particularly relevant to psychotic mental illness in which the sufferer may often deny illness (at least in psychiatric terms).

The influence of culture on patterns of help-seeking and subsequently service utilisation has received much attention in the social sciences. Aligning symptoms with an illness may not always result in seeking help however. In a sociological study modelling help-seeking by Zola (1973) it was found that people's responses to symptoms were contingent upon their cultural values and beliefs concerning health. In other words their perception of what is 'normal' plays a significant part. Subsequently, the decision to seek professional help is either promoted or delayed by social factors.

Zola (1973) outlined five triggers that he suggested are indicative of whether a person seeks help or not. These include experiences of interpersonal crisis, perceived interference of illness on physical and psychosocial activities and temporalising symptomatology. These triggers are represented in the following model outlined in Figure 5.

**Figure 5: Zola's model of help seeking**



Adapted from Crinson, I. (2007). Section 4. Lay Health Beliefs and Illness Behaviour. Retrieved from: <http://www.healthknowledge.org.uk/public-health-textbook/medical-sociology-policy-economics/4a-concepts-health-illness/section4>

For Zola (1973), resolving the physical or psychological aspects of health problems was only one of several reasons for seeking help. Other factors (such as going to work) may in fact be more salient to the person and influence their decision making process.

According to Zola (1973), people draw upon what is termed a 'lay referral' system which may include family, friends or they may engage in 'self-medication' or alternative therapies. Despite the additional element of social or cultural factors, these triggers are in line with several of the factors Mechanic (1968) indicates as influencing help-seeking (in particular needs competing with illness responses).

One of the interesting features of this model is that the decision to seek help does not necessarily lead to the utilisation of medical

professional services. What models of help-seeking and illness behaviour highlight is the social and culture fluidity of responses to illness and disease. Culturally-shaped beliefs about illness in individuals as well as the conceptualisation of illness by significant others both play a part in the ultimate responses to illness and decisions to seek help (Morgan et al., 2004).

#### **4.3.2 Explanatory health belief models and help seeking and their application to psychotic illness**

According to Rüdell, Bhui & Priebe (2009), two theories have dominated illness perception research: Explanatory Models and Illness Representations.

Becker and Maimon's (1983) Health Belief Model (HBM) has been a central explanatory model of disease and illness in determining how people respond to illness episodes and interact with the local Healthcare Systems. The HBM has been widely researched within the fields of social anthropology, medical sociology and cross-cultural psychiatry.

The corpus of evidence around health beliefs demonstrates a close relationship between cultural beliefs and help-seeking behaviour and a range of authors have documented how responses to illness tend to mirror the cultural framework within which individuals make sense of their experiences (for example, Campion & Bhugra, 1998; Patel, Simunyu & Gwanzura, 1997; Patel, Musara, Butua, Maramba & Fuyane, 1995; Helman, 1994; Leff, 1988; Marsella & White, 1982; Kleinman, 1980).

The HBM was originally based on four constructs representing *perceived susceptibility*, *perceived severity*, *perceived benefits*, and *perceived barriers* to seeking help for an illness. These concepts relate to people's "readiness to act." The concepts *cues to action*, (which would activate that readiness), and more recently *self-efficacy*, (or one's

confidence in the ability to successfully perform an action), have been added to the HBM (Rosenbock et al., 1988), to help the HBM better fit the challenges of changing habitual unhealthy behaviours, such as being sedentary, smoking, or overeating.

**Table 4: Components of the Health Belief Model**

<b>Concept</b>	<b>Definition</b>	<b>Application</b>
<b>Perceived Susceptibility</b>	One's opinion of chances of getting a condition	Define population(s) at risk, risk levels; personalize risk based on a person's features or behaviour; heighten perceived susceptibility if too low.
<b>Perceived Severity</b>	One's opinion of how serious a condition and its consequences are	Specify consequences of the risk and the condition
<b>Perceived Benefits</b>	One's belief in the efficacy of the advised action to reduce risk or seriousness of impact	Define action to take; how, where, when; clarify the positive effects to be expected.
<b>Perceived Barriers</b>	One's opinion of the tangible and psychological costs of the advised action	Identify and reduce barriers through reassurance, incentives, assistance.
<b>Cues to Action</b>	Strategies to activate "readiness"	Provide how-to information, promote awareness, reminders.
<b>Self-Efficacy</b>	Confidence in one's ability to take action	Provide training, guidance in performing action.

Adapted from Glanz, K., Marcus Lewis, F. & Rimer, B.K. (1997). Theory at a Glance: A Guide for Health Promotion Practice. National Institute of Health.

The premise of the HBM is that people will take action to undergo a health prevention behaviour when they are ready; they see it as beneficial; and the difficulty is not greater than what is to be gained. Readiness is determined by the consequences a health risk may impose. When perceived susceptibility is seen as likely and perceived severity of an illness is high, motivation increases. What is interesting in this model is that individuals may demonstrate behaviour to both take action and

avoid illness. The model however privileges the individual decision making process over the socio-cultural models of help seeking.

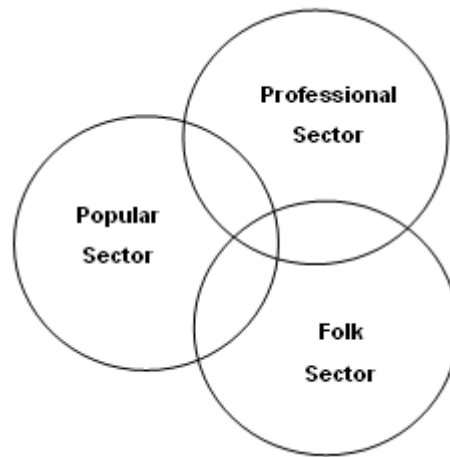
Mechanic and Zola's models of help seeking both highlight the role that available treatment resources play in illness behaviour. Based on a similar framework Kleinman (1980) proposed a model of Health Care Systems (HCS) which was built on the premise that the health-related components of all societies are more or less interconnected and form a cultural 'system'. For Kleinman (1980) the infrastructure of all health care systems are roughly the same across cultural boundaries, while the content varies with the social, historical, cultural and environmental circumstances of each system. The structure of health care systems, according to this framework, comprises three sectors - the popular, folk and professional - which overlap with each other to some degree (see Figure 6).

The professional sector consists of organized, legally sanctioned healing professions often based within the discipline of modern medicine (e.g. physicians, nurses, therapists). The term "professional" can include anyone acknowledged (through credentials), or perceived, in a culture as belonging to a professional group. In the folk sector, healers are non-professional and they have received little or no training in professional medicine.

According to Kleinman, healers in this sector are frequently classified as sacred or secular and are considered important because they have a special healing powers and take a holistic approach (often involving natural and supernatural (for example homeopathy)). The popular sector includes non-professional and non-specialist healers. It is at this level where medical problems are first recognized and defined and includes all the healing options that people use that do not fall into folk or professional sectors. Kleinman argues that illnesses are often self-diagnosed, and methods for treating them are based on this self-assessment or on the advice of family or friends. Healing and treatment may also be carried out in a religious setting.



**Figure 6: Venn diagram of Kleinman's Health Care Systems**



Essentially the HCS model places emphasis on available health care resources as well as the socially and culturally constructed illness beliefs and behaviours, which combine to shape help seeking practices in populations and sub-populations. What the above models assume is that individuals possess a complete, self-orientated and consistent set of health or illness beliefs overtime which can be measured against universals models.

Pesocsolido and colleagues (Pesocsolido & Boyer, 1999; Pescosolido, 1991), sought to overcome what was termed 'contingency approaches' to models of health belief and help seeking (a sociodemographic and clinical profile of service users at a particular time point is used to explore the correlations between these and other variables), from "process orientated" approaches (dynamic social process, involving the sufferer and significant others within the sufferer's social network, and influenced by the illness career of the sufferer), by proposing a model of Network Episodes (Morgan et al., 2004). Pesosolido's Network Episode Model (Pesocsolido & Boyer, 1999), argues that responses to health problems involve social processes that are managed through various contacts (or networks) within the individuals'

community, as well as the treatment systems and agencies available. Pesocsolido, based on the work of Clausen and colleagues (Clausen & Yarrow, 1955), mapped sequences of help seeking during the course of an individuals' illness. Responses to illness then, are a process of negotiating the meaning of symptoms within a social network over the course of the sufferer's illness (Morgan et al., 2004).

Illness representation research is based on the self-regulatory theory (SRT) (Leventhal, 1970) and originates from a psychological theory that explains individuals' behavioural response to physical threats. These threats or 'illness dangers' are assessed using two partially parallel processing systems (Rüdel et al, 2009); cognitive and emotional (Diefenbach & Leventhal, 1996; Leventhal, 1971).

Leventhal argued that individuals have cognitive and emotional representations of illness and that these representations and responses are continuously appraised leading to change and a self-regulated coping response (Rüdel et al, 2009). Cognitive representation of illness shares some of the theoretical underpinnings as explanatory models however it allows for learning and changes in the individuals emotional states.

SRT consists of several stages (Kanfer, 1970; Kanfer & Karoly 1972):

- The patient deliberately monitors their own behavior, and evaluates how this behavior affects their health.
- If the desired effect does not take place, the patient changes their behavior.
- Again if the desired effect is not realised, the patient reinforces the effect by continuing the behavior.

A further approach is for the patient to acknowledge and understand the factors involved in a health issue, and then decide upon an action plan for resolving the health issue. In this process the patient must monitor the results of their subsequent actions in order to evaluate whether there is a desired effect and whether changes to the action plan are needed (Leventhal & Nerenz, 1984).

Semi structured interviews for clinical settings have been devised for measuring illness perception and health belief based on Health Belief Models and SRT, as I will discuss in the next section.

#### **4.3.2.1 Measurement of psychotic illness beliefs using explanatory models**

*'...rarely does clinical practice systematically apply the process rules to elicit explanatory models and to maximise collaboration and communication between patient and professional.'* (Bhui & Bhugra, 2002, p. 181).

When explanatory models are investigated, the anthropological methodologies of participant observation and narrative research encourage authentic patient world view. However as Bhui and Bhugra (2002) explain there is a difficulty of uncovering explanatory models of mental illness during clinical interactions (due to the focus on making a diagnosis and introducing a treatment) and that when explanatory models of mental illness are uncovered they may include a variety of explanations that are either held simultaneously or taken up and dismissed rapidly (Williams & Healy, 2001).

Three instruments for measuring illness beliefs in patients with mental health have been traditionally used. The Explanatory Model Interview Catalogue (EMIC) and the Short Explanatory Model Interview (SEMI) have been suggested as tools for bridging the gap between qualitative and quantitative methods of gathering health belief data (Weiss, 1997; Lloyd et al., 1998). The SEMI in particular can be used in a semi-structured way to identify causal and other health beliefs and allows for discussion of the patient's problems, as well as exploring the different ways in which distress can be explained by using vignette material (Bhui & Bhugra, 2002).

Leventhal's SRT has also inspired the development of a standardised assessment for clinical settings: The Illness Perception

Questionnaire IPQ. The Illness Perception Questionnaire (IPQ) is another instrument typically used in research exploring models of illness belief. It includes a range of fixed causal explanations from which patients can identify the one closest to their own views (Weinman et al., 1996) but has been critiqued for not being in keeping with the aims of 'explanatory models' (Bhui & Bhugra, 2002).

A concern with methods for collecting data on health belief in mental illness, (and indeed of extrapolating models of physical illness to uncover mental illness beliefs), is that in psychological research in physical health, it is generally assumed that the sufferer's beliefs about an illness are internally consistent and relatively stable, or that coherent belief models are strived for.

Psychiatric patients, in contrast, may not have coherent beliefs about their ill health (Holzinger, Kilian, Lindenbach, Petscheleit & Angermeyer, 2003; Williams & Healy, 2001). For example, people suffering from schizophrenia frequently experience severe conceptual disorganisation (Docherty, 2005), meaning that constructions of illness may be confused, inconsistent, contradictory, or may even change during periods of mental stability and over the course of their illness. As Kinderman et al. (2006), noted conventional approaches to illness beliefs in physical health may suppose that the entity called an 'illness' can be appraised by or distinguished between an entity called the 'self' (Helman, 1994).

#### **4.3.2.2 Ethnicity, explanatory models of psychotic illness and help-seeking**

As we have explored in the previous section, illness behaviour and help-seeking are influenced by the immediate culture of the individual. Culture also plays a part in the interaction between conceptualisation of illness and utilisation of available health care services.

It would be true to say that all societies have an eclectic range of health care services, be it nationally-operated systems with regulated services, a collection of traditional or spiritually-based folk healers or black market organisations. Despite the success of Western medicine in treating numerous diseases, traditional, alternative and complementary approaches have continued to be utilised by numerous individuals as well as various groups in modern societies (Campion & Bhugra, 1998; Patel et al., 1997 & 1995; Leff, 1980).

As we have discussed in the previous section, decisions to seek help for an illness are dependent on the cultural and social beliefs and values of the individual with the ailment as well as their immediate socio-cultural network. They are also based on available treatment resources within that society or cultural sub-group.

An example of this would be popular beliefs in the Caribbean attributing 'madness' to the intrusion of spirits or the workings of black magic ('Obeah') which have been shown to influence interactions with local Health Care Services (such as traditional healers, obeah doctors and professional medical treatment facilities (Littlewood, 1988; Laguerre, 1987; Fisher, 1985).

The assumption that a social group share the same cultural understandings has been challenged by research investigating the relationship between ethnicity and health beliefs. In the UK an early study by Helman (1978) has shown how popular lay constructions of illness among White residents in north London predicted responses to illnesses and expectations of medical services. In addition, from the limited research examining mental health beliefs and explanatory models in minority groups in the UK there is a suggestion that traditional spiritual views and subsequent utilisation of culture-specific faith healers remain (Cinnirella & Lowenthal, 1999; Lloyd et al., 1998; Callan & Littlewood, 1998).

In a US study of mental health beliefs in the general population, Schnittker, Freese and Powell (2000), explored racial differences in the perception of the aetiology and treatment of mental illness. Using data from the 1996 General Social Survey they found that lay causal models fell into several distinct categories including Biological; Environmental; Social; and Spiritual. They found that African Americans were less likely than Whites to endorse a genetic or unhealthy family upbringing model of causation, although other forms of biological and environmental models of causation were used. They proposed that people from Black ethnic groups may be more sceptical of these causation models because of their alignment with racial stereotyping (e.g. arguments that position Blacks in a socio-economic disadvantage). They also found that racial differences in aetiological beliefs played a substantial part in explaining increased negative attitudes towards mental health professionals and treatment in Black groups compared to Whites.

In a more recent study in East London McCabe and Priebe (2004) used the SEMI to investigate and compare explanatory models of illness in White, West African, African Caribbean and Bangladeshi patients with schizophrenia. Focusing on measures of insight, treatment compliance, health locus of control, quality of life, treatment satisfaction, therapeutic relationships and symptomatology, biological, social and supernatural causes of illness were compared.

Whites were more likely to report biological causes than the three non-White groups, who reported supernatural causes more frequently. Whites also reported biological causes more frequently than African-Caribbeans and Bangladeshis; who reported social causes more frequently. McCabe and Priebe (2004) concluded that a biological explanatory model was related to enhanced treatment satisfaction and therapeutic relationships but not treatment compliance.

Studies investigating the views and conceptualisations of illness by family members of patients from minority groups have also highlighted possible differences in how Black Caribbean and White families respond

to mental illness, suggesting that more severe stigmatisation of mental illness in the Caribbean community may hinder voluntary help-seeking (Harrison et al., 1989).

Further studies looking at the relationship between doctor and patient have highlighted the role that ethnicity and culture can play in patient engagement and satisfaction with services, particularly when the patient and doctor do not share the same illness belief structures. For example, the tendency of some ethnic minorities to somatise emotional distress was found to result in difficulties in communication between the patient and a White doctor (Kleinman & Good, 1985; Racy, 1980).

#### **4.3.3 Explanatory health belief models and help seeking and their application and measurement in substance use disorder populations**

Literature addressing models of health belief which inform help seeking for substance abuse problems is limited. In a study by Bardsley and Beckman, (1988) the Health Belief Model (HBM) was used to study the utilisation of alcoholism treatment programmes in the US. Comparing a sample of 407 patients in treatment across all treatment centres in Los Angeles County and 203 patients not currently receiving treatment, patients were interviewed on each of the HBM components. Only two of the five HBM components (perceived severity and cues to action)-showed strong, consistent relationships with the decision to enter treatment. Women and men in treatment had higher perceived illness severity than those not in treatment. In addition, the in-treatment group reported a greater number of unusual events (cues to action) during the previous month than the not in treatment group (Bardsley & Beckman, 1988).

In another study the HBM was used to examine whether perceived susceptibility to and severity of two injection-related health conditions (non-fatal overdose and bacterial infections), as well as perceived

benefits of, barriers to, self-efficacy to, social acceptance of, and recent use of two harm-reduction behaviours (i.e., injecting test shots and pre-injection skin cleaning), predicted injecting drug users' near-term intentions to engage in these two harm reduction strategies.

Bonar and Rosenberg (2011) found that recent use of these two harm reduction strategies consistently and positively predicted near-term intentions in each of four drug-use situations (i.e. in withdrawal, not in withdrawal, alone, and with others). Perceived susceptibility to non-fatal overdose predicted intentions to do test shots, but only when participants imagined not being in withdrawal or injecting when alone. Perceived self-efficacy to clean one's skin predicted intentions to engage in this behaviour, but only when participants imagined injecting while not in withdrawal. Participants' ratings of how often other injectors in their social network engage in pre-injection skin cleaning was also a significant positive predictor of intentions to clean one's skin, but only when they imagined being in withdrawal.

Although there is a small corpus of literature relating to youth attitudes and health beliefs in substance abusers with comorbid HIV, to date there is little or no conclusive literature on ethnic differences in health beliefs of people with substance use disorders.

#### **4.4 LIMITATIONS OF APPLYING THESE MODELS TO COMORBID POPULATIONS**

It has been argued that significant modifications to models of help-seeking and health beliefs are necessary if they are to apply to mental disorders. As noted by Kinderman et al. (2006), it is probable that some of the assumptions underlying the models (particularly different dimensions of understanding which may be present in mental illness but not in physical illness) will be inappropriate. The same caution will no



doubt need to be applied to models of beliefs in populations with comorbid psychosis and substance use disorders. The additional belief structures surrounding substance use will need to be considered, added to which the likely inconsistency between cultural models of drug taking and mental illness which may lay blame in one construction and find victim in the other.

#### **4.4.1 Models substance use disorders in psychotic populations**

Lay models of causation are related to overall constructions of illness, and illness behaviours including help seeking. However there has been limited research into models of the aetiology of comorbidity. Much of the literature looking at aetiological theory of dual diagnosis has originated in traditional epidemiological research. There have been three broad hypotheses for the relationship between psychosis and substance use: Substance use as a risk factor for psychosis; Psychosis as a risk factor for substance use; and shared underlying risk for both disorders. There have been several theories proposed to help uncover this relationship, most of which have been generated within traditional epidemiological research.

Essentially the underlying question in terms of the relationship between substance use disorders and psychosis is which came first?

#### **4.4.2 Substance use disorder causes psychosis**

There is a body of evidence that suggests that stimulant abuse may be a risk factor for developing psychotic symptoms (Brady et al., 1991; Cohen, 1952; Curran et al., 2004). However this evidence does not show that this relationship may lead to a long and enduring psychotic illness (Gregg et al., 2007).

There has been much research over the past 20 years regarding the relationship between sustained cannabis use and schizophrenic disorders. Indeed, there is evidence to suggest that the main psychoactive component of cannabis,  $\Delta$ -9-Tetrahydrocannabinol (THC), can induce psychotic symptoms in healthy members of the general population (DeSouza et al., 2004; Morrison et al., 2009) and increase the sensitivity of the negative effects of cannabis in persons at risk of a psychotic disorder (Barkus et al., 2006; Verdoux et al., 2003).

In addition, recent studies have shown an association between cannabis use and chronic schizophrenic disorders (Moore et al., 2007) although evidence for direct causation is in its infancy. There is an increasing public awareness of the relationship between cannabis and schizophrenia, however little is known as to whether models of mental illness causation which include substance abuse differ by ethnicity and if these differences are reflected in illness behaviours and help-seeking.

#### **4.4.3 Psychosis causes substance use disorder**

The basis of this aetiological hypothesis is the self-medication hypothesis (SMH). This hypothesis suggests that individuals abuse substances to relieve psychotic and affective states that they find undesirable (Khantzian, 1985 & 1997).

The SMH has been applied to substance abuse and dependence in persons with psychotic disorders such as schizophrenia and it has been proposed that substances may be used to alleviate positive and negative symptoms of psychosis (e.g. Henquet et al., 2010; Chakroun, Johnson & Swendsen, 2010). It has also been proposed that substances may be used to alleviate the extrapyramidal side effects of antipsychotic medications (Schneider & Siris, 1987)

A criticism of this hypothetical model is that we would expect certain drugs that are abused in psychotic populations to be related to specific mental disorders depending on the weight of the psychotic and affective components of the illness. However, there is evidence that individuals with a severe mental illness abuse the same substances as the general population, just at an inflated rate (Addington & Addington, 2007). SMH has made its way into lay explanatory models of substance use in psychotic populations and no doubt plays a part in decisions to seek help for either disorder as I discuss in the following sections.

#### **4.4.4 Psychosis and substance misuse are derived from the same cause**

Genetic twin studies have provided the basis for evidence of the heritable nature of psychosis (Shih et al., 2004) and substance use disorders (Van den Bree et al., 1998; Cadoret et al., 1996). There has been limited research into a common genetic predisposition for both disorders with studies finding contradictory evidence (Gershon, 1988; Byrne et al., 2002).

Moreover, socio-economic factors that put individuals at risk for psychosis and substance abuse have been proposed as the common denominator in increased rates of substance use disorder in psychotic populations (Faris & Dunham, 1939) and little research has been conducted to ascertain whether this model is mirrored in lay constructions of comorbid psychosis and substance use disorders.

## **4.5 UNCOVERING CONSTRUCTIONS OF THE EXPERIENCE OF PSYCHOSIS AND COMORBID SUBSTANCE USE**

*'Beliefs about health and illness shape emotional responses to illness, health-related behaviour and relationships with health care providers in physical illness'. (Kinderman et al., 2006, p. 1900).*

It would be fair to say that the truth of this statement for psychotic illness has been evidenced in the previous sections. Very few studies however, have looked qualitatively at constructions and conceptualisations of psychotic illness and comorbid SUDs or health beliefs in this population. Research into health beliefs has tended to focus broadly on severe mental illness or schizophrenic populations or substance abusing populations separately.

There has been limited qualitative research in areas where these populations overlap (as we saw in Chapter 3) and even less that looks at the role ethnicity may play in constructions of illness and substance use.

As Bhui and Bhugra (2002) note, Kleinman's original work involved asking questions through an exploratory process of qualitative enquiry. Bhui and Bhugra (2002) argue that this leads to complex and multi-layered responses which provide information about social rituals, symbols in communication, types of knowledge and illness narratives. It is these illness narratives that help build a more detailed picture of conceptualisation of illness and provide the basis for generating new theory and models of health belief.

The aim of this section is to exemplar qualitative investigation in psychiatry, psychology and the social sciences which have used qualitative approaches. We have seen how qualitative methodology in the form of structured and semi-structured questionnaires (EMIC, SEMI and IPQ) can elicit models of mental illness belief in patients with psychosis. It is also useful however to draw on research which doesn't use pre-existing models of health belief as a framework.

These studies may challenge health belief models of illness or use entirely different frameworks of understanding to uncover constructions of illness and substance use. Not surprisingly this type of research is scarce in the area of comorbidity.

#### **4.5.1 Constructions of mental illness in psychotic populations**

In a study by Kinderman et al. (2006) the beliefs about illness experiences of 20 patients diagnosed with schizophrenia (10 currently psychotic inpatients and 10 outpatients in remission) were examined using qualitative interviews and thematic analysis. The study sought to clarify and extend possible conceptual differences between illness belief structures in physical health, based on explanatory models such as HBM and SLT and on doubts about both the existing methodological approaches, and the conceptual frameworks which underpin them. The study recruited patients purposively from local inpatient and outpatient's mental health services in the Liverpool area who were over 18 years of age with a diagnosis of schizophrenia. Twenty patients (10 inpatients and 10 outpatients) were interviewed.

The interviews were conducted using a semi-structured interview guide, which listed key areas to be explored, including patients' beliefs about: the reasons that they entered psychiatric care; associated experiences; any illness labels, such as 'illness', 'schizophrenia' or 'depression', that they or others had applied to their problems; the effects and mode of action of treatments they had been offered. Questioning was responsive to the participants' own comments and situation, so the ordering and amount of time spent on each of these areas varied between interviews.

All inpatients at the time of interviewing were experiencing psychotic symptomatology (hallucinations, delusions or formal thought disorder) as assessed by the clinical team in charge of the patients' care.

Conversely, all outpatients were confirmed by the clinical team in charge of them to currently be in a period of relative remission.

The analyses of interview transcripts used elements of grounded theory (Dey, 1993) and were conducted in parallel with data-collection so that aspects of the developing analysis could be tested and developed in subsequent interviews. Thematic analysis was performed by all authors.

80% of the sample was male and all but two participants described themselves as White British. The study found different conceptualisations of illness between inpatients and outpatients as highlighted in Tables 5 and 6.

**Table 5: Properties of the beliefs of the inpatient sample**

Properties of the beliefs
<p>The inseparability of illness from patients' identities:</p> <ul style="list-style-type: none"> <li>• psychotic problems inseparable from the patients' wider lives, sense of self and spiritual and moral issues</li> <li>• psychosis not appraised as a 'thing' apart from the appraiser</li> </ul> <p>The flexibility and uncertainty of beliefs:</p> <ul style="list-style-type: none"> <li>• absence of consolidated 'models' of illness in acute psychosis</li> <li>• inconsistent and fluid beliefs about psychotic problems</li> <li>• puzzlement and confusion</li> </ul> <p>The social dimensions of illness labels:</p> <ul style="list-style-type: none"> <li>• patients have a strong tendency to own the use of labels such as 'psychotic' and 'schizophrenia'</li> <li>• such labels experienced as statements about the individual and with moral as well as descriptive significance</li> <li>• models and labels concerning psychotic problems are commonly experienced as pejorative</li> </ul>

Adapted from Kinderman, P., Setzu, E., Lobban, F. and Salmon, P. (2006). Illness beliefs in schizophrenia. p. 1904.

**Table 6: Properties of the beliefs of the outpatient sample**

Properties of the beliefs
<p>Patients' separation of current self from past experiences:</p> <ul style="list-style-type: none"><li>• 'illness models' discernible during periods of relative remission</li><li>• periods of psychosis viewed as autobiographical episodes</li><li>• psychosis described as a state of detachment from reality</li></ul> <p>Illness labels:</p> <ul style="list-style-type: none"><li>• labels such as 'psychotic' and 'schizophrenia' remain perceived as statements about the individual</li><li>• models and labels concerning psychotic problems are commonly pejorative</li></ul> <p>The social and psychological elements of illness labels:</p> <ul style="list-style-type: none"><li>• discussion of 'illness', but also psychosocial stress, morality and spirituality</li><li>• accounts of past psychotic experiences enmeshed in other aspects of the patients' lives and part of the sense of self</li><li>• integration of physical, social and other approaches implied and idiosyncratic</li></ul> <p>Hopelessness and resignation:</p> <ul style="list-style-type: none"><li>• unremitting hopelessness</li><li>• resignation and a lack of personal agency</li></ul>

Adapted from Kinderman, P., Setzu, E., Lobban, F. and Salmon, P. (2006). Illness beliefs in schizophrenia. p. 1906.

The themes identified in the two samples show that patients currently experiencing psychosis did not identify their experiences as separable 'illnesses' and did not have coherent and consistent models of illness belief. Patients currently in a period of remission evaluated their experiences as distinct from their own normal behaviour, but used

conceptual frameworks of understanding that were not in line with conventional 'health belief' models.

What is evident from the constructions in both samples is that 'self' is a salient feature of understanding illness whereas the appraisal of symptomology in patients' immediate social networks such as family and friends (an important aspect in both Mechanic's (1968) factors influencing illness behaviour and Zola's (1973) model of help-seeking) does not feature as expected.

What should be noted is that this study does not look at constructions of substance use or substance use disorders in either sample. It is likely that there would be differences in the conceptualisation of illness and its relationship to self in a sample of patients with co-occurring problems with drugs or alcohol. Nevertheless, what this study does highlight is that patients' ways of understanding mental illness do not necessarily parallel those described in physical illnesses.

Boydell et al. (2010) conducted a review of qualitative studies examining constructions of psychotic experience. They found 31 papers summarising 27 studies conducted in FEP populations across the world. Findings were organised according to interpretive philosophies of general social processes (GSP) (Prus, 1996 & 1997) such as: achieving identity; acquiring perspectives; doing activity; and developing relationships.

Six of the studies focused on the subjective experience of psychosis under the GSP 'achieving identity'. Boydell et al., (2010) found that young people who have experienced their first episode of psychosis seek to find meaning for their psychotic experiences and adopt multiple explanations over time (Hirschfeld et al., 2005; Kilkku, Manukka & Lehtinen, 2003; Larsen, 2004; Perry, Taylor & Shaw, 2007; Werbart & Levander, 2005; Sin, Moone & Wellman, 2005).

One study (Larsen, 2004) found that knowledge gained from psycho-educational interventions allowed respondents to better understand symptoms and these understandings were found to help them control



reoccurrence of those symptoms. Another study (Kilkku, Manukka & Lehtinen, 2003) found that respondents identified the role of receiving information about their experiences early on in their treatment journey and how this created a sense of relief as well as providing a tool for future symptom management.

Boydell et al. (2010) found that several of the studies (Fisher & Savin-Baden, 2001; Larsen, 2007; McCann & Baker, 2001; Newton et al., 2007; O'Toole et al., 2004; Sin, Moone & Wellman, 2005) reviewed focused on the respondents' views of early interventions services and these themes collectively were related to 'acquiring perspectives' as part of GSP. Respondents talked about the importance of the relationships they had with services. Additionally the personal qualities that providers brought to that relationship were considered just as important as the therapeutic frameworks they used.

Findings relating to 'doing activity' included the subjective experience of help-seeking. Three studies identified barriers to help-seeking which included: the time it took to receive a diagnosis; unreturned phone calls; and the lack of communication between various service providers (Bergner et al., 2008; Corcoran, 2007; Czuchta & McCay, 2001). Four of the studies examined the recurring features of the help seeking pathway and demonstrated that when symptoms persist, significant others begin to search for answers through a wide range of professional sources. The role of social networks was also found to be significant in many studies.

In addition many of the studies reported findings on 'experiencing relationships'. Themes within these studies revealed the importance of peer relationships to young people with FEP as well as descriptions of the experiences of multiple difficulties feelings of isolation and stigmatisation.

Although this review was thorough and included studies from a range of geographical populations, all the papers have been reviewed within one philosophical leaning and may not have been re-analysed or grouped according to the original authors' theoretical framework.

#### **4.5.2 Constructions of substance use in comorbid populations**

In one of the few qualitative studies that has looked at the lived experience of patients with psychosis and substance use disorders, Bradizza and Stasiewicz (2003) in the US found that in a group of patients with severe mental illness (SMI) (psychotic and severe affective disorders) and substance use disorders (SUD) several interpersonal and intrapersonal factors influenced the situational risk for using substances.

Using a focus group methodology, which included ten audio-taped focus group discussions with patients that were currently in treatment at a centre for dual diagnosis, participants were asked questions regarding general social situations they found difficult to manage as well as the perceived benefits and problems resulting from alcohol and drug use.

Participants were also asked about high-risk situations or “triggers” for substance use. The qualitative data were analysed using a multi-level process that focused on the classification of responses related to high-risk drug and alcohol use situations. Two raters independently identified all instances in which a participant mentioned a high-risk situation and coded the situation into a classification system developed independently of the other rater.

Qualitative data analysis uncovered ten themes that encompassed 33 high-risk situations for substance use. These included:

- Psychological symptoms (avoiding or coping with symptoms such as paranoia, auditory hallucinations and feelings of anxiety or nervousness).
- Positive and negative affect (positive and negative emotions triggered drug and alcohol use including: feeling good, bad, sad/depressed, angry, bored, frustrated, lonely, stressed/overwhelmed and guilty).
- Reminders of substance use (being around certain people, environments or objects that had been highly associated with substance use often led to drug and alcohol use).

- Being around people who use drugs and alcohol (encountering people with whom they have previously used drugs, being around friends who use, friends who pressure use, seeing one's partner drunk or high and being around family members who use substances).
- Interpersonal conflict (negative interpersonal interactions such as arguments with family members, criticism about their alcohol or drug use and having people criticise or try to control them).
- Offers of drugs or alcohol (difficulties in avoiding drug use, particularly since they were frequently offered drugs by others).
- Experiencing loss (not getting anywhere in life, death of a family member and having their children removed by Social Services).
- Receiving money (government assistance, borrowed money from family or friends or money they obtained from strangers as a trigger for use).
- Loss of appetite (for women only: knowledge that they have not been eating due to an absence of hunger can be a trigger to smoke marijuana, which increased their hunger).
- Being abstinent (having been abstinent for a while can generate strong urges to use a substance).

The study findings were compared to literature on risk for substance use in SUD populations without SMI and suggested that individuals with an SMI and SUD experience a number of unique high-risk situations that differ from those reported by non-SMI substance abusers.

Patients with SMI and comorbid SUD experience several categories of high-risk situations that are commonly found among SUD patients without SMI, including the experience of unpleasant emotions, urges or temptations to use substances, conflict with others, social pressure to use substances, enjoying pleasant times with others and pleasant emotions.

However, Bradizza and Stasiewicz (2003) found that there were significant differences between the two groups. Unlike patients with SUD only, patients in this study did not report physical discomfort or testing

personal control as high-risk situations. They did however highlight high-risk situations unique to this comorbid population including psychological symptoms, experiencing loss, receiving money, loss of appetite and being abstinent.

As well as having important implications for the measurement of the prevalence of substance use in populations with psychotic disorders (or vice versa as it was intended) this study also provides a basis for the development of relapse assessment instruments and treatment strategies appropriate for dual diagnosis populations.

In relation to understanding why patients with comorbidity (despite having poorer outcomes than patients with just psychosis) are likely to continue using substances this study highlights two things. Firstly, despite the obvious negative effects of substances (such as symptom worsening) substance use in psychotic populations can be just as enjoyable as it is in the general population. Secondly, self-management and mastery of psychosocial stresses through self-medication is likely to be key.

In addition, this study highlights how patients with comorbidity have cumulative stresses and life difficulties to contend with (such as dealing with the physically and socially addictive elements of substance use and difficulties with family members because of substance use), compared to patients with only a psychotic disorder, that would have an undeniable impact on substance use and psychotic relapse.

Moreover the added pressure of family monitoring of both substance use and signs of recurring mental illness remains a double edged sword. It may provide additional support within a larger coping framework. but is also provides additional pressure (including feelings of disappointment) and increased likelihood of contact with drug treatment and mental health services which may account for the elevated rate of hospital admissions in this group.

In an early nineties study by Noordsy et al. (1991) subjective experience of alcohol use in a sample of schizophrenic patients in an outpatient community mental health treatment centre in New Hampshire uncovered several positive effects of prolonged alcohol use. Using a structured interview schedule and reporting responses of 'sometimes' or 'often' to having a particular experience, 75 patients were interviewed about their psychotic symptoms and alcohol use.

Over half of the sample reported that alcohol use improved social anxiety, tension, dysphoria, apathy, ahedonia and sleep difficulties. Although only 15% of respondents reported that alcohol was used to relieve psychotic symptoms, self-medication for psychotic symptoms was associated with lifetime alcohol use disorders. Positive effects on non-psychotic experiences were also associated with lifetime alcohol use disorders

Archie et al. (2013) conducted a study that sought to identify factors that contribute to the initiation of alcohol and illicit drug use in young patients with FEP. Forty-five participants were recruited from five early intervention programmes located across Ontario. Eight focus groups were conducted which involved four to six participants per group. Thematic analysis was used to systematically code transcripts from the focus groups for concepts, patterns and themes that related to initiation of alcohol and illicit drug use. The participants were not asked explicitly about substance use, but they discussed their experiences with alcohol and drug use spontaneously during every focus group.

Three main themes relating to the initiation of substance use were identified.

- 1) facilitating social interaction: illicit drugs appealed to respondents because substances provided a social context and a means for interacting with other young people. The social experience of substance use was seen as shaping respondents personality, values and interests.
- 2) self-medicating: some individuals used substances to help

reduce unwanted symptoms. Respondents used substances to reduce stress, but this reason was often fleeting.

3) altering perceptions: substances altered experiences, were considered pleasurable and created a more interesting world helping them to develop a new sense of being

Archie et al. (2013) note that their study has several limitations including failing to categorise substances into classes even though different types of substances may have had different effects and including a group of healthy controls to compare responses to.

## **4.6 CONCLUSIONS**

Despite a large corpus of epidemiological literature detailing the association between comorbid psychosis and substance use disorders the underlying mechanism of this relationship is still up for debate. The negative outcomes (such as more frequent relapse and more hospitalisations) of dual diagnosis may be better explained by models of health belief and help-seeking that place the health behaviours including decision making processes of the suffer within a wider socio-cultural context. Furthermore, ethnic differences in prevalence and correlates of comorbidity may also be better understood through exploration of the differences in individual's models of mental health belief (including models of illness aetiology) as well as constructions of psychotic experience and substance use within the context of their mental illness. As discussed in earlier chapters there is a need for robust longitudinal population-based studies, which can explore the various interactions ethnicity may have with comorbid diagnosis.

This PhD study aims, through a mixed method study design, to estimate the prevalence of comorbid psychosis and substance use disorders in different ethnic groups, giving special attention to Black African and Black Caribbean populations. It also aims to explore in detail

the relationship between comorbid diagnosis and various clinical and psychosocial outcomes as well as uncover patient perceptions of psychotic illness, substance use and service responses within different ethnic populations. Chapter 6 summarises the method used in this study. However, the following chapter first provides a summary of the philosophical stance within which the study is framed. It also provides detailed discussion of the necessary theoretical and methodological considerations of using a mixed method design for investigating this phenomena.

#### Chapter Summary 4.

Chapter Summary
<p><u>Aims of the Chapter:</u></p> <p>To highlight the limitations of epidemiological research in understanding the experience in patients with comorbid psychosis and substance use. To provide an overview of models of help seeking, health beliefs and lay constructions of experience of psychosis and substance use and how they may relate to lay understandings of comorbidity.</p> <p><u>Key Points:</u></p> <ul style="list-style-type: none"> <li>• Ethnic differences in prevalence and correlates of comorbidity may be better understood through exploration of the differences in individual's models of mental health belief</li> <li>• Negative outcomes may be better explained by models of health belief and help-seeking that place the health behaviours, including the decision making processes of the suffer within a wider socio-cultural context.</li> </ul>

## **CHAPTER 5: THEORETICAL CONSIDERATIONS**

### **5.1 SUMMARY OF SCIENTIFIC JUSTIFICATION**

The aims of this chapter are to situate and give reason to the methodological design of the PhD study. To do this we need to first understand the origins of research methodology and methods used in social enquiry. I will outline and discuss the ontological/epistemological assumptions in and compliments and contentions between quantitative and qualitative methodology. This will lead onto a discussion of the common belief of the incompatibility of quantitative and qualitative methods; an overview of the epistemological flexibility of some methods and methodologies; and how quantitative and qualitative methodologies are not necessarily incompatible as well as why the methodological approach of combining these two methodologies is increasingly being used in health service research. I will also discuss a 'middle ground' position of subtle realism and its ontological and epistemological appropriateness for mixed methods research and this study.

### **5.2 SHAPING THE DISCIPLINE**

To understand research in mental health (or more specifically mental health services research) one must look at the disciplines that guide it and more importantly the underlying philosophical assumptions and scientific axioms that underpin it. Much of the research discussed in the previous chapters spans a range of disciplines; psychology, social psychiatry and anthropology, as well as various areas of research interest: health research, mental health and addictions. It is necessary then to acknowledge these areas of influence and the philosophical discussions which cultivated the study.



### **5.2.1 Ontological and epistemological debates in the 'soft sciences'**

Traditionally much of research conducted within the realm of social science (namely psychology, social psychiatry, sociology and anthropology) has used quantitative methodology (Murphy et al., 1998) and those wishing to uncover events, characteristics and patterns in health (epidemiology) have tended to use quantitative methods to do so.

Quantitative enquiry is often situated within a realist ontological perspective (Murphy et al., 1998). Pure realists assume that it is possible to state objective truths about the material world (Murphy et al., 1998). Qualitative enquiry sits at the other end of the theoretical spectrum. In contrast to quantitative enquiry it has been argued by leading writers on social research epistemology and methodology that the appropriate or 'legitimate' epistemological paradigm for qualitative research is constructivism (Guba and Lincoln, 1989; Denzin & Lincoln, 1994a; 1994b; Guba, 1990; Lincoln & Guba, 1985). Constructivism (in Psychology) or constructionism (in Sociology) have an idealist ontology.

Indeed much of qualitative enquiry is framed within idealist ontology and constructionist epistemology (Smith, 1983a; 1983b; 1985; 1989). Scientific idealism holds that the external world consists merely of representations and is a creation of the mind (May & Williams, 2002). Constructivism adopts a similar position (Guba & Lincoln, 1989). It rejects the idea that the world is made up of facts to be uncovered (Palmer, 1928); instead any objective knowledge or truth can be reduced to a perspective (Scwandt, 1997). Constructivism has been termed a 'relativist' or 'subjectivist' position which could be held in opposition to the traditional 'objectivist/empiricist' approaches that have dominated scientific enquiry (Lincoln & Guba, 2000).

With the increased use of qualitative methodologies a scientific 'paradigm war' began in the 1980s. Because quantitative and qualitative enquiries were seen as being situated in different and opposing scientific paradigms (Smith, 1995; Murphy et al. 1998, p. 4) and thus each were inseparably bound to a set of specific and incompatible ontological and epistemological (i.e. realist and constructivist) assumptions they could not be combined (Greene, 2007).

This notion has been contested. For example, Hacking (1999) argues that a social constructionist (or constructivist) approach to researching a phenomena can be employed at both global and local levels (i.e. that everything we know about a phenomena is socially constructed or that elements of it are). The idea that an individual phenomena in its creation is subject to socio-historic and political influences and that in, for example an alternate reality, it might well be different (i.e. a 'social construction') is not incompatible with realist stances (i.e. that it is knowable). Similarly Shadish, Cook and Campbell (2002) argued that "all scientists are epistemological constructivists and relativists" in the sense that they believe that *both* the ontological world and the worlds of ideology, values, etc. play a role in the construction of scientific knowledge" (p. 29). In other words it is possible to approach research with a realist ontology but a constructivist epistemology (Maxwell, 2011), a notion that is discussed more fully in the next section.

### **5.2.2 Finding a common ground: a Subtle Realist perspective**

Qualitative work is often identified with idealism while quantitative work is identified with realism. Hammersley has argued that neither realist nor idealist (or constructivist) approaches offer a sound philosophical basis for social research (Hammersley, 1992). Instead, an approach that sits between naïve realism and relativism/idealism would be a more appropriate research stance; subtle realism. Murphy et al. (1998) summarises subtle realism in the following way:

*"If we adopt a subtle realist position we are able to hold on to truth as a regulative ideal, while, at the same time, accepting that it will always be impossible to be absolutely certain that truth has been attained in any particular instance. This allows us to assess both qualitative and quantitative research in terms of two fundamental criteria – those of validity and relevance"* (Murphy et al., 1998, p. 11).

I argue however that subtle realism is not simply 'sitting on a paradigmatic fence' or a 'middle ground' along an ontological or epistemological spectrum. Instead it is a combination of both seemingly opposing stances, and according to Murphy et al. (1998) can be considered as an ideal epistemology for a mixed method study as both quantitative and qualitative methodologies can be assessed under the same two criterion (relevance and validity) (Murphy et al. , 1998).

Subtle realist perspective is based on the belief that 'truth' is a regulative ideal, that phenomena exist independently of the knower's claims about it yet it is impossible to be certain about claims of knowledge of 'truth'. Any given reality can be represented from a range of different perspectives and each of these representations may be treated as true. The objective of research should be to search for knowledge about which we can be 'reasonably confident'. Such confidence in our representation of reality will be based upon judgements about the credibility and plausibility of knowledge claims (Hammersley & Atkinson, 1995).

Similarly, Hamilton's (2002) definition of knowledge as beliefs in which one can have reasonable confidence in their validity or truth, falls in line with what Hammersley (1992) considers a 'common sense' understanding and consensual notion of what constitutes social knowledge. Andrews (2012) considers this to be a 'pragmatic view of knowledge': a knowledge which involves judging truth in relation to what is already known, not by appeal to philosophy.

Murphy et al. (1998) set out the three key elements of subtle realism according to Hammersley (1992):

1. Absolute truth in knowledge which the knower can be certain of is not possible. This is because claims to valid knowledge are based on assumptions that are presupposed an often axiomatic. Truth should be reinterpreted as "beliefs about whose validity we are reasonably confident" (Hammersley, 1992, p. 50).
2. It is essentially possible to claim to have knowledge of a phenomena that is independent of the phenomena itself (i.e. the claim or belief does not change reality in order to make the phenomena true or false), and that this knowledge will be more or less representative of the phenomena.
3. The aim of social research is to represent rather than reproduce reality and that phenomena can be 'represented' from multiple perspectives.

(Murphy et al., 1998, p. 174)

We can extend the understanding of subtle realism by looking at Philips' (1990) argument that just because observations or claims to knowledge are based upon perspectives or theory it doesn't mean that we cannot judge between them. Phillips (1990) also argued that it is possible to combine a commitment to the social construction of reality with an aim for 'truth', through studying the different constructions of reality people make without accepting that only particular beliefs are true.

As Murphy et al. (1998) states about subtle realism: '*This middle-way allows us to accommodate some elements of social constructivism, without abandoning a commitment to independent truth as a regulative ideal [idealism].*' (Murphy et al., 1998, p. 69)

Similarly, much like the view held by Shadish et al. (2002) and Maxwell (2011), Banfield (2004) observed that the underpinnings of

subtle realism is this medley of realist ontology and constructivist or idealist epistemology. In his critique of Hammersley, Banfield (2004) asserted that the ontological claim within subtle realism is a realist one: phenomena exist independent of human knowledge of them. However he believes that this is then 'set against constructivist accounts of social reality, the social world contains objects whose existence does not depend upon what we think about them' (Banfield, 2004, p. 54). This realist ontological position aligned with a constructivist or relativist epistemology is not too dissimilar to a critical realist approach (whereby phenomena are knowable but there is an emphasis on the 'fallibility of human knowledge') (Banfield, 2004, p. 54).

Maxwell (2011) in Soini et al.'s (2011) *Epistemologies for Qualitative Research* argues that realism 'can do useful work' for qualitative methodology. He proposes four main areas where a realist perspective can make contributions: (1) causality: the legitimacy of this concept in qualitative research, and the contributions that qualitative research can make to causal explanation. (2) The understanding of mind and mental phenomena: the value of a realist understanding of these, one that does not reduce them to brain states or behaviour. (3) diversity: seeing diversity as a real phenomenon, rather than as "noise" or "error" that obscures the essential commonalities in different individuals, events, or situations. (4) validity: how we can assess the value, credibility, and quality of qualitative research.

As Murphy et al. states: "Subtle realists accept that material reality can itself be a constraint on the possibility of definition. We can only perceive the world in ways which are in some sense consistent with the immanent organisation of that world. (Murphy et al., 1998, p. 4). As I have discussed above the marriage of a realist ontology and a constructionist or Idealist epistemology is not only compatible with both quantitative and qualitative enquiry it facilitates the use of both these research methods within one single study (a notion that is discussed in more detail below).

### 5.2.3 Theory in research process

The design of a research study and the research process used within it are closely linked to the ontological and epistemological assumptions it holds to. Quantitative research process as well as mostly being aligned to realist research philosophy finds its origins with Popper (1959). Popper, as summarised by Chalmers believed that science starts with a problem which then leads to falsifiable hypotheses which can be tested (Chalmers, 1982). This deductive (hypothetico-deductive theory) and falsification process were not concerned with the source of the hypothesis. Many who follow the research theories of Glaser and Strauss (1967) see qualitative research as an inductive process. Glaser and Strauss opposed the imposition of *a priori* theory upon data and asserted that the researcher should seek to generate 'Grounded Theory' (Murphy et al., 1998).

Interestingly, Murphy et al. (1998) states that "much contemporary qualitative work stresses its inductive character, while quantitative work tends to stress its deductive character. In fact, it is clear that good science involves both for different purposes at different times." (p. 2).

These methodological 'research process' perspectives (founded in either realist truth seeking or Idealist perspective seeking frameworks) relate to the underlying logic, or ways of thinking about the data and should be connected to but distinguished from other parts of research process (Johnston, 2004). For example Johnston outlines the thoughts of Erlandson et al. (1993) (an advocate for naturalistic rather than laboratory research settings) in which he distinguishes, the method, which refers to types of data (i.e., quantitative or qualitative), from the tools used in data collection (i.e. quantitative survey instruments or qualitative interviews), and the techniques for analysing the data (i.e. statistical methods or thematic analysis) from the logical process of conducting research (Johnston, 2004).

In the same way seemingly opposing ontology's and epistemologies can be combined so too can opposing research processes. Johnston (2004) describes the practical process of triangulation in a mixed method doctoral study (similar to that of less fundamental applications of Grounded Theory), involving both deductive and inductive process. For her, the quantitative data was analysed deductively yet, "...the overall iterative process of data interpretation involving between-methods data triangulation was inductive" (p. 267).

Similarly to many of the authors referred to in the previous section, Patton (1988), argued for a "paradigm of choices". In other words paradigms should not be considered to be rigid or fixed, and researchers should not have to choose between two opposing paradigmatic camps. Patton proposed that "different methods are appropriate for different situations" (p. 119) and that "wherever possible, multiple methods should be used" (p. 136). Johnston (2004) infers that implicit in this statement is a support for mixed method research even within one study: "...indeed, that both inductive and deductive reasoning can be complementary, rather than mutually exclusive, data analysis tools" (Johnston, 2004, p. 262). I shall discuss this in more detail in the proceeding sections.

As Wallace (1978) posits, scientific process involves both induction and deduction in a circular, rather than linear process. In other words qualitative research being inductive and quantitative research being deductive is another assumed dichotomy which doesn't hold in practice.

### **5.3 MIXED METHODOLOGY IN SOCIAL SCIENCE RESEARCH**

Mixed methods research has been used throughout the 20<sup>th</sup> and 21<sup>st</sup> century. Since the 1930 and 40's quantitative and qualitative methods in sociology and social psychology have been used side by side in social

enquiry (Hammersley & Atkinson, 2007) and that it was after the rise of 'logical positivism' when qualitative research began to be seen as belonging to an alternate scientific paradigm (Murphy et al. 98). There is a large corpus of literature around the philosophical and practical possibilities, benefits and constraints of mixing quantitative and qualitative research within one study. As I have discussed earlier it is possibly theoretically at least to combine opposing research paradigms and processes but what are the practical implications of that?

### **5.3.1 Mixed methodology in Health Services Research**

Maxwell's (2011) exposition of Epistemological Heuristics in Soini, Knronqvist and Huber's 'Epistemologies for qualitative research' (2011) argues that it 'is not simply that qualitative research can be conducted from a number of different ontological and epistemological perspectives. In addition there are significant advantages to incorporating diverse, even "contradictory," epistemologies in one's conceptualization and practice of qualitative research' (p. 11).

A notion cultivated by Green (Green, 2007 & 2008; Greene & Caracelli, 1997) who refers to mixed methodology (either quantitative and qualitative or several different types of qualitative research) as not only a 'dialectic stance' (a paradigmatic 'conversation' within a single study where it is important to value each in their own right) toward mixing paradigms (Greene & Caracelli, 1997; Greene, 2007) but also as a distinctive methodology in its own right (Green, 2008). The specific ways in which quantitative and qualitative research methodologies and methods can be combined is discussed in the next section (5.3.2) but essentially the premise behind their combined use is that the disparate conversations between them provide us with deeper understanding of the phenomena.



Historically, health services researchers in the UK have tended to use quantitative methods to investigate issues in health care provision (O’Cathain, Murphy & Nicoll, 2007). As Murphy et al. (1998) note we may establish by the methods of social epidemiology that certain kinds of health risks are unequally distributed within a population (Murphy et al., 1998). In the last decade or so health services research has welcomed the use of qualitative approaches (Pope & Mays, 1995). Mixed methods research is relatively common in Health Services Research in the UK now and pragmatic rather than ideological reasons have often been given for using mixed methodology in one study. Other reasons have included the perceived deficit of quantitative methods alone (O’Cathain, Murphy & Nicholl, 2007).

Qualitative methods are often employed in addition to quantitative methods when little is known about the topic area (Morse & Field, 1995), and there has been a renewed interest in mixed methods research in the health services research field in general (Barbour, 1999).

### **5.3.2 Mixed methodology models**

Mixing quantitative and qualitative methods can be done in several ways. Murphy et al. (1998) outlines three ways in which quantitative and qualitative methodologies can be combined within one study; qualitative research as a junior partner; ‘horses for courses’ (the choice and combination of types of research methods should fit the research aims); and qualitative research as a senior partner. These models are concerned with the weighting of quantitative and qualitative research within one study.

The first and the last types of mixed method design speak for themselves. Qualitative research being used as a junior partner was born out of the attitudes many social scientist had towards qualitative research. Murphy et al. (1998) refers to the works of Dean, Eichhorn and

Dean (1969) who advocated the use of 'unstructured' methods when quantitative methods could not be used for example in hard to reach groups or as an exploratory exercise in new areas of research interest to help generate research hypothesis. For Murphy et al. (1998) the axiomatic assumptions of this mixed methodology are clear: there is a hierarchy to the methods used for knowledge creation with the traditional 'objectivistic' or idealist, statistical methods being at the top.

In contrast, research as a senior partner has an opposing assumptive basis; qualitative research methods in a 'battle for the best' win out. Murphy et al. (1998) discusses the position of Becker and Geer (1969a and 1969b) to illustrate this. They proposed that participant observation provided the most 'complete' accounts in sociological enquiry. 'Completeness' however, was only one side of a multifaceted evaluation criterion that can be used to measure appropriateness of a research method; along with other philosophical and practical criteria, relevance, accuracy and reproducibility should also be considered.

The 'horses for courses' mixed methodology has a more complicated philosophical process. The question that needs to be asked when using this type of methodology is 'what is the best combination of methods?'. To answer that question you must first ask the question 'what do you want to know?' (Silverman, 1997). This approach to mixed method design traditionally is based on the premise that your choice in methods is related to what you are trying to find out. Similarly to the other two approaches where qualitative methods have either a junior or senior role in the research design the issue is one of determining the best way of either measuring or understanding the thing we need to know. Here there is no hierarchy to either quantitative or qualitative methods (Murphy et al., 1998).

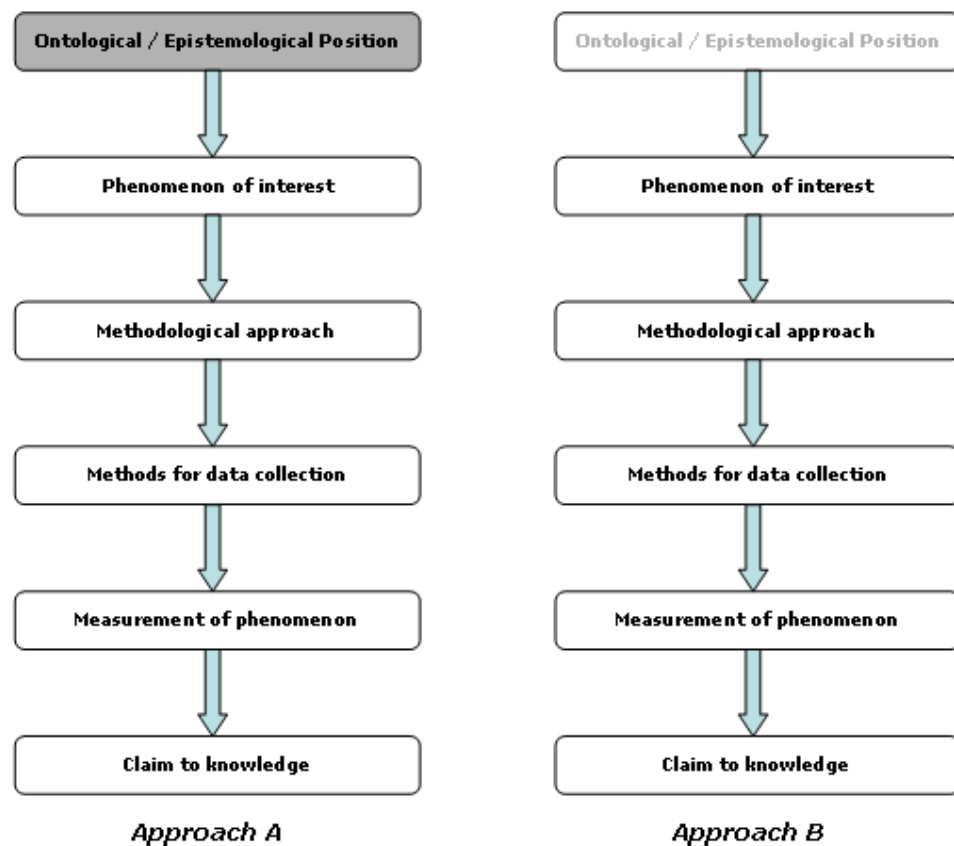
As I have suggested in the previous sections it is also a question of your ontological and epistemological approach. Should researchers choose a method from a methodological 'tool-kit' that is 'best for the job' or should the epistemological or more importantly the ontological

underpinnings of a method or methodological approach be the decider in its use? Turning briefly then to the above question, I consider there to have been two ways of thinking about approaches to mixed methodology design and quantitative/qualitative weighting (see Figure 7).

Approach A bears close resemblance to Murphy et al.'s (1998) research as a junior or senior partner. The ontological and epistemological standpoints are fixed and considered together. From these standpoints decisions about methodology and method are made. For example, when a constructivist perspective is employed then the idea of representing the 'truth' becomes irrelevant and the choice of method becomes a question of whether it assumes the same ontological and/or epistemological stance that the researcher aligns them self to.

It is not surprising then that constructivist researchers use qualitative methodologies and methods such as case studies to examine, describe, de-align concepts and phenomena and may have quantitative methods as a junior partner. Conversely realist researchers tend to use data collection methods that enumerate so data can be tested against a hypothesis (e.g. large scale surveys).

**Figure 7: Approaches to mixed method design**

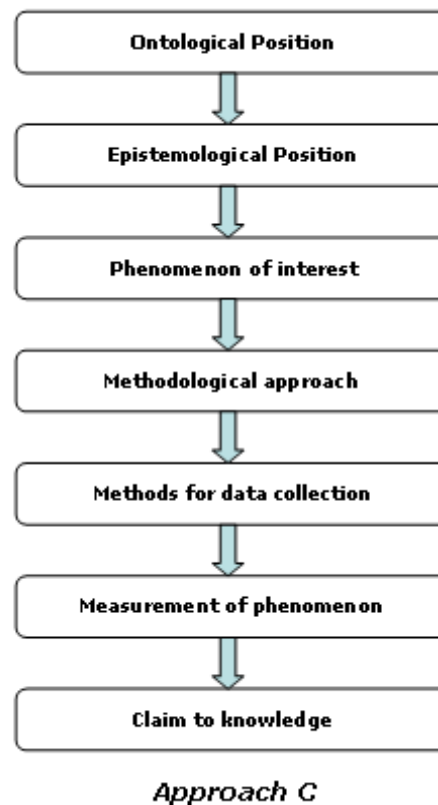


However in approach B the initial steps (consideration of ontological and epistemological position) are considered together but they are assumed and left out of the conscious research design decision making process. This clear lack of attention paid to philosophical standpoints is often how psychiatric and psychological research is conducted with obvious realist axioms (i.e. that there is a knowable and measurable truth and it is the type of question you ask that determines the method you use to answer it).

Coming back then to what Murphy et al. (1998) term a 'horses for courses' perspective on mixed method design, this approach I propose has an assumed (most likely realist) philosophical basis (i.e. Approach B). It is this position that enthuses some of the earlier writings on a 'horses for course' type perspective on mixed methodology (e.g. Trow, 1970; Vidich & Shapiro, 1969).

What is needed then is an approach (see Figure 8) which combines the approach of Murphy et al. (1998) and Maxwell (2011). That not only allows for flexible methodological considerations but also flexible philosophical considerations as well.

**Figure 8: Approaches to mixed method design**



In this approach to mixing methodologies, ontology and epistemology can be separated out (e.g. a subtle realist approach that combines a realist ontology with a constructionist epistemology). Realism and idealism (or constructivism) can be considered tools which can be taken from an epistemological tool-kit (Abbott, 2004; Maxwell, 2011), and quantitative survey questionnaires and qualitative semi-structured in-depth interviews can be considered tools from a methodological or method tool-kit (Murphy et al., 1998). In other words this approach allows for a deeper more varied 'tool-kit' from which to choose the

appropriate methods for measuring phenomena and making knowledge claims.

Although these models or approaches are useful, there are other considerations when thinking about mixed method design. There still needs to be an emphasis on the quantitative-qualitative weighting of a design. Models which tackle issues such as timing and theoretical mixing (particularly at the analytical and interpretation phases), as well as how quantitative and qualitative data are going to be integrated, have been developed (Creswell & Plano Clark, 2007; Creswell & Plano Clark, 2011; Kettles, Creswell & Zhang, 2011).

Designs have been split into two main types; sequential and concurrent. This refers to the timing of each phase of the research. Sequential designs have the quantitative and qualitative phases running one after the other whereas concurrent designs run the phases at the same time. For each of these there are 6 variants; convergent (triangulation); embedded; explanatory; exploratory; transformative; and multiphase (see Table 7)

The idea of convergent designs is to produce different but complementary data on the same topic (Morse, 1991). Embedded designs are used when one set of data is not considered enough to answer a research question. One phase (often the qualitative) is embedded with in a larger phase of the research project as a supporting role so to speak (Kettles, Creswell & Zhang, 2011). Explanatory mixed method designs are two phase designs. One type of data (usually quantitative) is collected but then followed up with a further qualitative phase to gain in-depth meaning of the first phase. The exploratory design is similar to the explanatory design in that the two types of data are collected in two separate phases however weighting is usually given to the qualitative phase (Kettles, Creswell & Zhang, 2011).

Creswell and Plano Clark (2011) added two additional mixed method research designs in their second edition of *Designing and Conducting*

Mixed Methods Research. The transformative design is a design that the researcher shapes within a transformative theoretical framework. A transformative theoretical framework is a framework used for advancing the needs of underrepresented or marginalized populations and it involves the researcher being sensitive to the needs of the population of interest, and using research to inform recommendations for strategic/political change to improve social justice for that population (Creswell & Plano Clark, 2011).

As Greene (2007) argues, the purpose for mixing methods in the transformative design is for value-based and ideological reasons more than for methodological or practical reasons relating to data collection procedures. In other words the aim is to use the methods that are best suited for advancing the transformative or ideological goals of the study.

Lastly the multiphase design the multiphase design combines both sequential and concurrent designs, usually within a time-limited program of study with an overall program objective. Quantitative and qualitative approaches are used to support the development, adaptation, and evaluation of specific programs. It provides an overarching methodological framework, and is particularly useful in developing multiphase, complex mental health nursing research projects (Creswell & Plano Clark, 2011).

**Table 7: A summary of the major mixed methods research designs**

Design	Variants	Timing	Weighting	Mixing
Convergent parallel (triangulation)	1. Convergent 2. Data transformation 3. Validating quantitative data 4. Multilevel	Concurrent: quantitative and qualitative at the same time	Usually equal	Merge during the interpretation or analysis
Embedded	1. Embedded experimental 2. Embedded correlational	Concurrent or sequential	Unequal	Embed one type of data within a larger design using the other type of data (transformation)
Explanatory	1. Follow-up explanations 2. Participant selection	Sequential: quantitative followed by qualitative	Usually quantitative	Connect the data between the two phases
Exploratory	1. Instrument development 2. Taxonomy development	Sequential: qualitative followed by quantitative	Usually qualitative	Connect the data between the two phases
Transformative	Advocacy lens (e.g., feminist perspectives, critical theory),	Concurrent or sequential	Unequal	Connect or transform the data between the two phases
Multiphase	Overarching methodological framework for large scale projects	Concurrent or sequential (sandwich)	Usually equal	Embed data from phase in the next phase (merge, connect or transform data)

Adapted from Creswell J.W. and Plano Clark V.L. (2007) *Designing and Conducting Mixed Methods Research* and Creswell J.W. and Plano Clark V.L. (2011) *Designing and Conducting Mixed Methods Research* (2nd edition).



Quantitative and qualitative designs produce different type of data. One of the challenges of mixed method designs is how to treat these data. Creswell and Plano Clark (2007) propose three strategies for mixing or integrating data; merging, embedding, connecting. The assumption of mixing data is to maximise the strengths and minimizes the weaknesses of each type of data.

Merging data involves combining the qualitative data (e.g. texts or images) with the quantitative data (e.g. numeric information) by reporting results together in a discussion section of a study. For example, a person could first report the quantitative statistical results followed by qualitative quotes or themes that support or refute the quantitative results. Another method for merging data is to transform the qualitative dataset by counting occurrences of themes so that it can be compared with the quantitative data (Sandelowski, Voils & Knafl, 2009).

An alternative to merging data is to connect the two types of data. This involves analysing one dataset and then using that information to inform subsequent data collection for another dataset. In other words, the integration occurs by connecting the analysis of results from the initial phase (e.g. quantitative data collection) with the data collection from the second phase of research (e.g. qualitative data collection).

The last method for merging data is embedding data. With this type of data integration, a dataset of secondary priority is embedded within a larger, primary design (e.g. qualitative research as a junior or senior partner). While no type of data mixing is privileged we need to consider the overall mixed method design we are utilising when deciding how best to integrate data.

## 5.4 QUALITATIVE METHODS

Having considered the philosophical and methodological aspects of mixing quantitative and qualitative research I now turn to the question of what qualitative methods are best used in mixed methodology? Having a 'tool-kit' of methods is useful but which methods will get the 'job done' in epidemiological and health services research?

Although there are several methods used in qualitative research including questionnaires, interviews, participant observation and secondary research techniques such as document analyses or conversational analyses, the most common forms of qualitative methods used in social science research are interviewing methods or participant observation (Murphy et al., 1998).

Silverman (1985) has argued that the advantage of observational research is that it is able to produce representations of the way in which people actually behave. Conversely questionnaire and interview data only produce idealised accounts of attitudes and behaviours which bear uncertain relation to actual real situations. In a similar vein Strong (1979a) argued that what people say in an interview situation depends upon what questions have been asked and that interview responses may not take into account difficulties of immediate recall.

Some of the difficulties of using participant observation in mixed method research however are obvious, such as time and money (particularly if qualitative research is being done alongside a large survey). Murphy et al., (1998) outlines several areas where interviews are useful including; accessing the respondent's definitions and interpretations; penetrating respondents' public accounts; and flexibility in exploratory research. In health services research they are particularly useful for uncovering what beliefs and attitudes underlie particular kinds of health behaviour and what might encourage change in health-related behaviours and as Murphy et al., (1998) states "If you want to understand what people do, believe and think, ask them" (p. 112).

Denzin (1970) identified three types of interview:

- The standard schedule interview (question working and order are standardised for every respondent)
- The non-schedule standardised interview (a topic list is of information required from each respondent is devised but the wording and order of questions is flexible)
- The non-standardised interview, (no specific set of questions is employed. Interviews are primarily conversational)

Denzin (1970) has argued that standardised non-schedule and non-standardised interviews offer the advantage of allowing for detailed constructions of their view of the world as well as allowing respondents to raise salient topics. These types of interview are also known as semi-structured and depth interviews (Britten, 1995).

Standardised or structured interviews have been used in help-seeking research for example Sheikh and Furnham (2000), used the Mental Distress Explanatory Model Questionnaire (MDEMQ), (Eisenbruch, 1990) to examine the relationship between cultural beliefs and causes of mental distress and the desire to seek professional help for mental health problems. This questionnaire is a 45-item questionnaire, developed with items derived from the Murdock et al. (1978a & 1978b) categories, with additional items covering western notions of physiological causation and stress.

Structured qualitative interviews have been critiqued for arising from the positivist assumption and eliciting a 'body of facts' from respondents (Silverman, 1985; Murphy et al., 1998). In addition Cicourel (1964) has argued that while it may be possible to standardise question wording and order, it is impossible to standardise behaviour exhibited in the interview (interviewer and interviewee).

As I discussed in the previous chapter giving an overview of models of illness belief and help seeking, three instruments for

measuring illness beliefs have been traditionally used. These instruments have tended to be of semi-structured nature and the Explanatory Model Interview Catalogue (EMIC) and the Short Explanatory Model Interview (SEMI) have been suggested as tools for bridging the gap between qualitative and quantitative methods of gathering health belief data (Weiss, 1997; Lloyd et al., 1998). The SEMI has been used in a semi-structured way to identify causal and other health beliefs and allows for discussion of the patient's problems, as well as exploring the different ways in which distress can be explained by using vignette material (Bhui & Bhugra, 2002).

Unstructured interview techniques have also been used in psychiatric health services and addictions research. Stenhouse (2011) used unstructured interviews to gather narrative data on patient experiences of acute psychiatric inpatient care. Holistic analysis of the narratives produced several themes of experience including help, safety and power. Although unstructured interview methods may elicit detailed narratives they are difficult to perform with large sample sizes and may generate data from which empirical generalisation is difficult to make (Martin & Stenner, 2004; Neale, Allen & Coombes, 2005).

Bhui and Bhugra (2002) have argued that illness narratives may help build a more detailed picture of conceptualisation of illness and provide the basis for generating new theory and models of health belief. It would be true to say then that methods which allow for deep exploration of respondents constructions in a fairly systematic way while simultaneously providing room for respondents to divulge salient narratives (that may not have been considered a priori) are key.

## 5.5 SAMPLING

Murphy et al. (1998) has discussed a number of different approaches to qualitative study sample selection. Four broad types are identified:

- probability sampling
- opportunistic sampling
- non-random sampling for representativeness
- theoretical sampling.

Two considerations should be given when sampling for qualitative research: Whether the intention is to make empirical generalisations or theoretical generalisation. The first and third approaches described by Murphy et al. (1998) are concerned with what empirical generalisation, whereas the fourth is concerned with theoretical generalisation (Hammersley, 1992). The second approach however, is typically not considered generalisation. The second, third and fourth approaches are all considered forms of purposive sampling (Kuzel, 1986).

A prerequisite in empirical generalisation as Hammersley (1992) emphasised, is that the population to which generalisation is to be made is adequately defined. For example non-probabilistic sampling methods can be used to demonstrate the typicality of a setting being studied. Alternatively theoretical sampling may be used to test a theoretical issue. For example, theoretical sampling may be used in an on-going way over the course of a research study to help develop and refine theoretical propositions which emerge from the research (Murphy et al., 1998). For Murphy et al. (1998), sampling decisions in qualitative research should be pragmatic and systematic: opportunistic sampling should be avoided if possible.

Ritchie and Lewis (2003) propose a third type of generalisation. They argue that empirical generalisation can be separated into two areas; generalising to the population within which the study sample is taken; and generalising to wider contexts. They therefore suggest three

concepts for generalisation: representational generalisation (generalisations from study sample to its parent population); inferential generalisations (generalisations from study sample to wider/other contexts; and theoretical generalisation (theoretical propositions drawn from the study findings). Differences in these types of generalisations should be considered not only when sampling but also when interpreting qualitative research findings.

## **5.6 THE PHD STUDY**

The starting point for the PhD study was its ontological and epistemological positions. This which has been discussed in detail in section 5.2 was that of subtle realism. Given the flexibility of this philosophical standpoint a mixed method design was proposed for the investigation of ethnic differences in prevalence, correlates and illness/substance use constructions of patients with comorbid psychosis and substance use disorders. The study used a mixed method approach, in part because of complexity and sensitivity of the subject matter to the study population. In addition there is also an increasing demand for research to inform policy and practice, which for Health Services Research is now leaning towards the use of both quantitative and qualitative methods simultaneously (O'Cathain, Murphy & Nicholl, 2007).

The PhD study utilised a sequential design, that was part explanatory part exploratory. The findings from the qualitative study attempted to explain in part, the findings of the quantitative study. However much like the works of Dean, Eichhorn and Dean (1969) the qualitative study was used to explore the impact comorbidity might have on perceptions of the usefulness of treatment services by unveiling constructions. It also aimed to help generate future research hypothesis.

Choosing this type of mixed method design (as I have touched on in the preceding sections), requires consideration of various methodological

issues. These issues include the priority or weight given to the quantitative and qualitative data collection and analysis in the study, the sequence of the data collection and analysis, and the stage/stages in the research process at which the quantitative and qualitative phases are connected and the results are integrated (Creswell et al., 2003).

Much of the nature of the design of the PhD study was determined by the AESOP-10 follow-up study (discussed below) which formed the basis of the first quantitative phase of the PhD study. This study began data collection in 2007 after extensive tracing of patients who took part on the AESOP baseline study. Data from both studies was connected (data from the AESOP-10 study and first quantitative phase was used to inform participant selection in the second phase). Since partial analysis of the AESOP-10 data was needed to identify eligible participants for the second phase, data collection for the qualitative study did not begin until 2008.

As mentioned above, in sequential designs the quantitative data are usually collected and analysed first and then followed by the qualitative data collection and analysis. The weighting of these studies are usually in favour of the quantitative phase and data analysis is often connected (Creswell et al., 2003; Hanson, Creswell, Plano Clark, Petska & Creswell, 2005). However the quantitative and qualitative arms of the PhD study can be considered to have equal weighting.

The next chapter outlines the method utilised in the PhD in more detail, including sampling and recruitment for both phases.

## **5.7 THE REFLEXIVE PROCESS AND REFLEXIVITY**

Insider perspective is paramount to qualitative research (Fetterman, 1989). However it is always difficult to disentangle the etic perspective of the researcher from the emic perspective of the respondent (Pike, 1990).

An emic perspective, or insider standpoint, represents the viewpoint of the members of a culture or group being studied or observed; while an etic viewpoint reflects more the perspective or values of the researcher, that is, an outsider stance (Pike, 1990). Reflexivity plays a part in illuminating etic perspective. The term reflexivity refers to being sensitive to the researcher's presence in the research process and how it has contributed to the data collected and how their own priori assumptions have shaped the data analysis (Murphy et al., 1998).

Essentially conscious self-reflection should play a part in all qualitative research and attention to the fact that the findings of research are inevitably shaped by the research process itself should be considered. Interview data reflect the social relationships within which they are embedded and Altheide and Johnson (1994) believe that when drawing conclusions from data, the researcher should reflect upon his or her own impact upon the setting. The credibility of research findings can also be enhanced when reflexive practices are used (Marshall, 1985).

Murphy et al. (1998) outlines several ways an assessment of the impact of the researcher can be made. These include comparing the interviewee statements from interview data and normal everyday talk with others (Silverman, 1989) and monitoring changes in the data obtained over time (Guba & Lincoln, 1989). A number of authors have recommended that the self-conscious monitoring of the researcher's impact upon the setting should be carried out alongside the data collection.

For example prompts, probes and encouragement are features of semi-structured interviewing. Prompts are typically considered cues that an interviewer may use to remind the respondent about an event. Probes involve getting the respondent to say more about a particular topic and encouragement is also used in verbal and non-verbal form to get a respondent to continue speaking about an event or topic. Emerson and Pollner (1988) have talked about the concept of the Transactional context in interviewing, whereby the way the researcher frames his questions and



probes interviewees may tacitly direct or pre-structure the responses received. Paying attention to this type of interviewer affect during data collection as well as analysis is one way of being reflexive.

LeCompte and Goetz (1982) suggest that taking time out away from the interview to reflect) and possibly taking notes about the research process are also useful reflexive processes. However whatever process is employed a researchers' claim to credible knowledge (an important concept in all realist research) will be strengthened by a demonstration on reflexivity in data collection, analyses and conclusions (Murphy et al., 1998).

## **5.8 CONCLUSIONS**

I have discussed the origins of quantitative and qualitative research, where quantitative enquiry has traditionally been situated within a realist ontological perspective, while much of qualitative enquiry has been framed within idealist ontology and constructionist epistemology.

Because quantitative and qualitative enquiries have been viewed as being situated in different and opposing scientific paradigms the combination of them within one study has not historically been considered. However, through the marriage of a realist ontology and a constructionist or idealist epistemology (Subtle Realism) I have argued that is possible to combine a quantitative epidemiological study with a qualitative investigation within a single study design. This is the perspective which frames the PhD study.

Several models of mixed method study design have been proposed, each with different emphasis on the qualitative component, however the model most appropriate for answering the research hypotheses and questions should be utilised. Various qualitative methods for exploring patient constructions have been discussed. However methods that allow for deep exploration of respondents conceptualisations (such as

interviewing techniques) in a fairly systematic are considered the most appropriate.

When using qualitative research methods, consideration of the sample and sampling method or techniques should be given. Specifically, the issue of generalisability should be considered. Differences in the types of generalisation that can be made from qualitative or mixed method research should be considered not only when sampling but also when interpreting qualitative research findings. Furthermore emic perspective is paramount in qualitative research. Subsequently reflexive techniques should be used where possible.

#### Chapter Summary 5.

Chapter Summary
<p><u>Aims of the Chapter:</u></p> <p>To situate and give reason to the methodological design of the PhD study. To critically discuss theoretical and methodical approaches to mixed method design and the appropriateness of these for addressing the aims and objectives of the PhD study.</p> <p><u>Key Points:</u></p> <ul style="list-style-type: none"><li>• Quantitative and qualitative enquiry should not be considered incompatible within a single study</li><li>• A Subtle Realist perspective may be considered as an appropriate theoretical stance within which to frame mixed method study design</li><li>• It is useful to consider individual methods as being part of a larger methodological 'tool-kit' where decision for utilisation is based on what is 'best for the job' (i.e. answering the study hypotheses or research questions)</li><li>• Issues of generalisability should be considered when sampling for qualitative studies</li><li>• Respondent (emic) perspective is important in qualitative research and Reflexivity can play a part in illuminating researcher (etic) perspective</li></ul>

## **CHAPTER 6: METHODOLOGICAL STRUCTURE AND DESIGN OF THE STUDY**

### **6.1 OVERVIEW OF THE EPISTEMOLOGICAL AND METHODOLOGICAL FRAMEWORK FOR THE STUDY**

The PhD study is situated within a subtle realist position which holds that knowledge is socially constructed, but that these constructions are constrained by the world existing 'out there'. This perspective is situated between a constructionist or idealist perspective that sees truth as a matter of personal belief and a realist perspective which maintains that the external world exists independently of or representations of it (Murphy et al., 1998).

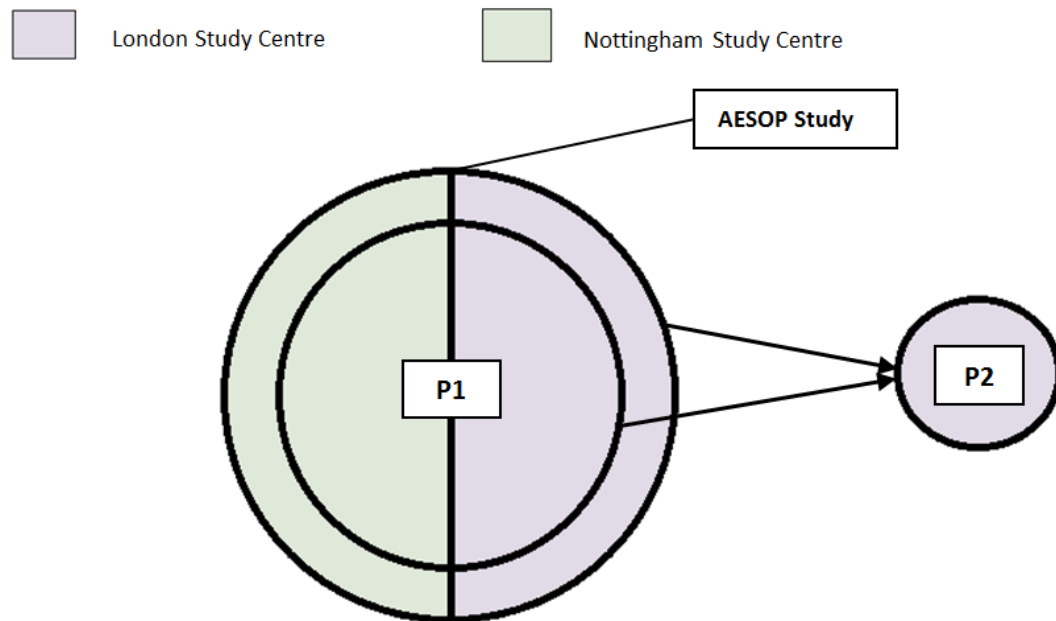
The study combines, (using a sequential design, part explanatory part exploratory with both a deductive and inductive research process) a quantitative epidemiological study (Phase One) with a qualitative study (Phase Two).

### **6.2 STUDY DESIGN AND HYPOTHESES**

The PhD study was nested within the larger MRC funded AESOP-10 (Aetiology and Ethnicity in Schizophrenia and Other Psychoses) follow-up study which looked at the course and outcome of psychosis in an ethnically diverse cohort of psychiatric patients (N = 557) being followed-up 8-12 years after their first presentation to services (see figure 9). As we have discussed in the previous chapter the study adopted a part exploratory, part explanatory sequential design whereby the qualitative

study was conducted after the data collection for the AESOP-10 study and first phase of the PhD study had been completed.

**Figure 9: Venn Diagram of PhD Study Design**



P1 – PhD Study Phase 1; P2 = PhD Study Phase 2

### **6.2.1 Study population**

As I will discuss in more detail in the following sections, the study sample was drawn from the larger AESOP-10 sample. The AESOP-10 study followed up patients who made contact with psychiatric services between 1997 and 2000 in two distinct geographical areas; South London and Nottingham.

In the London centre patients presenting to psychiatric services in the South London and Maudsley (SLAM) mental health trust were included. The SLAM NHS Trust is divided into four boroughs: Southwark; Lambeth; Lewisham; and Croydon. The trust also provides specialist services in Bromley, Bexley and Greenwich. These areas have been found to have high levels of mental health need (Hatch et al., 2012). They also have high proportions of ethnic minorities and migration.

Lambeth for example, has the second highest proportion of Black Caribbean people in the country. It also has the second highest proportion of Black Caribbeans born in the Caribbean, behind Lewisham (Lambeth Census Headlines, 2011). Lambeth ranks 5th for Black African people and it has the highest proportion of mixed race White / Black African and multiple / mixed ethnic group in the country. Southwark and Lewisham equally have high proportions of Black African, Caribbean and Mixed race residents.

In the Nottingham centre patients presenting to psychiatric services in the Nottingham City area were included. There is a long history of migration in Jamaican, Indian and Pakistani groups to Nottingham, however according to the 2001 census around 81% of the population were from a White British ethnic group (2011 Census Nottingham City Key Statistics, 2012).

### **6.2.2 Aims and objectives**

The overall study objectives of the PhD study were to:

- 1) To make a theoretical and methodological contribution to the understanding of the relationship between comorbidity of psychosis and substance use disorder and ethnicity.
- 2) To estimate the prevalence and correlates of comorbidity of psychosis and substance use disorder in different ethnic groups.
- 3) To describe service responses to and explore perceived quality of care of patients with comorbid diagnoses from different ethnic populations, with special attention to Black Caribbean and Black African groups.

### **6.2.3 Hypotheses and research questions**

The two primary hypotheses tested in the first quantitative arm of the study were:

- 1) The prevalence of comorbid substance use disorders in individuals with an 8-12 year history of psychosis will differ according to ethnic group. More specifically, rates of comorbidity will be higher in Black Caribbean, and lower in Black African, patients than White patients.
- 2) In all ethnic groups, comorbid substance use disorder will be associated with:
  - a) more frequent relapses,
  - b) more compulsory admissions andindependent of potential confounders, including age, gender, diagnosis and study centre.

In other words, the study hypotheses propose that a greater prevalence of comorbid psychosis and substance use disorders in the Black Caribbean group will contribute to poorer outcomes over the 8-12 year follow-up period. Similar patterns would not be evident for Black Africans or other ethnic groups.

The second, qualitative phase of the study, which purposefully selected a sub-sample of patients from the AESOP-10 cohort, investigated the following research questions:

- 1) How do individuals with comorbidity of psychosis and substance use disorders construct their experiences of 'psychosis' and drug and alcohol use 8-12 years after their first-episode?
- 2) How do individuals with comorbidity of psychosis and substance use disorders construct their experiences of mental health and substance abuse treatment services?

- 3) What is the perceived role (if any) of family, friends and other social support networks in the treatment process for 'psychosis' and substance use disorder?

In other words the second arm of the study aimed to both describe if and how the problem of comorbidity differs for ethnic minorities in psychotic populations and to identify conceptualisations illness and substance use. The study also aimed to explore the impact comorbidity might have on attitudes towards the perceived usefulness of treatment approaches (namely hospitalisation, community treatment) and the role family, friends and alternative forms of support play in the recovery process.

## **6.3 PHASE ONE: QUANTITATIVE INVESTIGATION**

### **6.3.1 Sample**

The sample for the quantitative arm included patients that were eligible for inclusion in the AESOP-10 follow-up study which I discuss in the next section. The findings from the 2001/2002 British Crime and Drug Survey have estimated drug use in Black African groups to be significantly lower than in Black Caribbean or White ethnic groups (Aust & Smith, 2003). Equally high rates of psychosis have been found in Black Caribbean and Black African groups (Sharpley et al., 2001), with numerous studies showing these groups are at greater risk of compulsory admission to hospital (Bhui et al., 2003; Morgan et al., 2004; Morgan et al., 2005) and more likely to be treated in secure and forensic settings (Bhui et al., 2003; Morgan et al., 2004). The first arm of the PhD study specifically looked at uncovering differences between these ethnic groups.

### *Study Inclusion and Exclusion Criteria*

Phase One of the PhD study used similar inclusion and exclusion criteria as the AESOP studies. The AESOP baseline study inclusion criteria for cases were:

- a) age between 16 and 65 years;
- b) resident within tightly defined catchment area of South-East London;
- c) presence of a first-episode of psychosis (F10-F29 and F30-F33 in ICD-10 (WHO 1992)) within the time frame of the study; and
- d) No previous contact with health services for psychosis.

The additional inclusion criteria for cases in the PhD Phase One study were:

- e) White British, Black Caribbean or Black African ethnicity
- f)

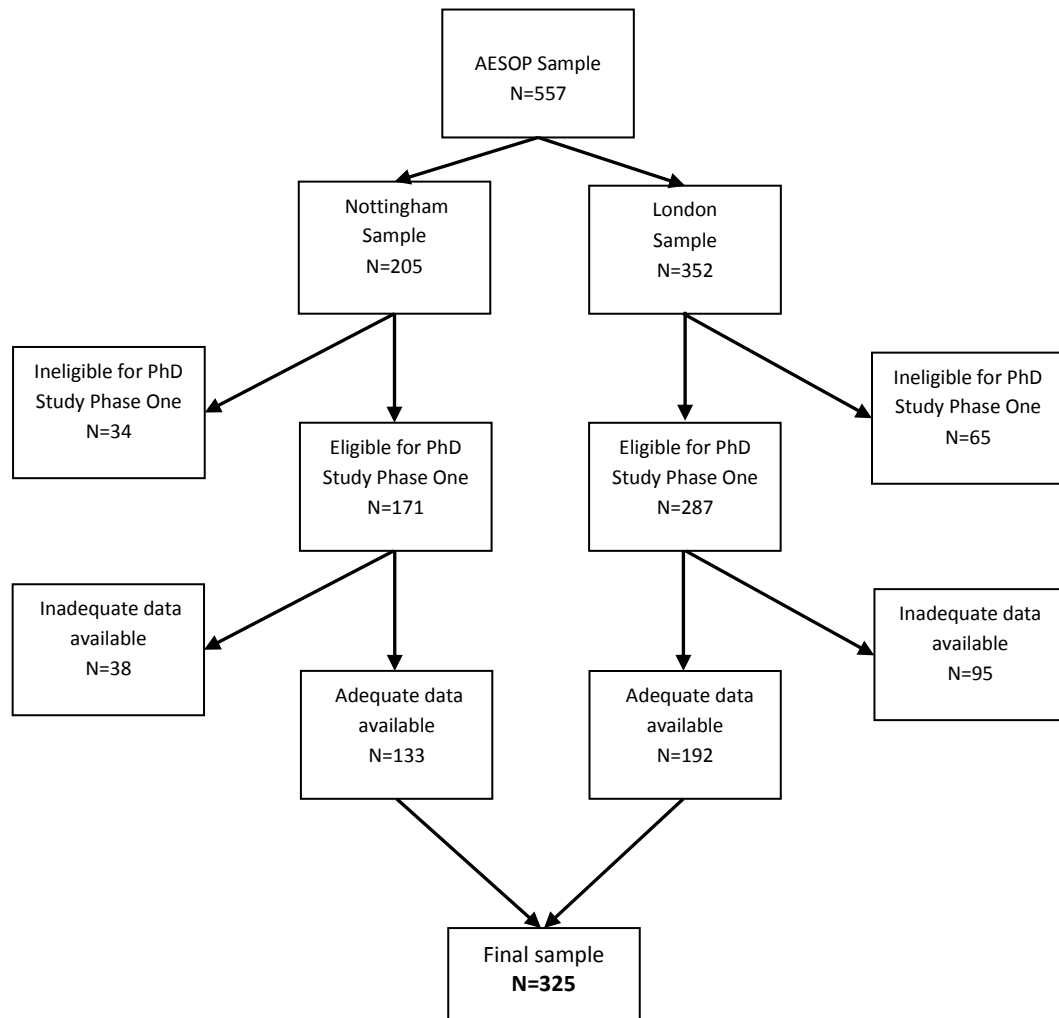
The exclusion criteria for cases were:

- a) evidence of psychotic symptoms precipitated by an organic cause;
- b) transient psychotic symptoms resulting from acute intoxication as defined by ICD-10;
- c) IQ less than 50; and
- d) previous treatment for psychosis

Figure 10 summaries the final sample for the first phase of the PhD study. The total AESOP sample was 557. Phase One of the PhD study was only concerned with patients from White, Black Caribbean and Black African ethnic groups, so patients not belonging to those groups were not included (N=99) leaving an eligible sample of 458. Due to information being limited for patients with a follow-up of less than eight years and because of patients who had died or moved abroad, resulting in a final sample of 325.



**Figure 10: PhD Phase One sample**



### 6.3.2 Study power

The study's primary hypothesis in the first phase focused on the prevalence of comorbid diagnoses in different ethnic groups. In one of the very few studies to provide any data on this, Afuwape et al. (2006) found a prevalence of comorbid cannabis use and psychosis of 40% in their Black British group, compared with 6% in their White group. This study had high statistical power to detect such differences. A power analysis calculation was performed before data collection had been completed to estimate the study power assuming a conservative difference in prevalence of comorbidity of 20% between White patients and either Black Caribbean or Black African patients. A two group test

with a 0.05 two-sided significance level was estimated to have 80% power to detect the difference between a White patients with 30% prevalence of comorbidity and Black Caribbean patients with 50% prevalence of comorbidity (odds ratio of 2.333) when the sample size in each group is 103.

The study aimed to estimate risk for comorbidity while controlling for potential confounders. The more variables you have in a model, the more power is reduced. In general, a recognised rule of thumb is that 20 subjects per predictor variable in regression analysis is acceptable. However, researchers might have better power to detect a small effect with approximately 30 participants per variable. Wilson VanVoorhis & Morgan (2007) have outlined Cohen and Cohen's (1975) guidelines for multivariate analysis: for regression analysis with five predictors and a population correlation of .30, 187 participants would be needed to achieve 80% power. Assuming a sample size with 103 patients in each group using multivariate analysis the PhD study was expected to have high statistical power to detect ethnic differences in prevalence of comorbidity.

### **6.3.3 The AESOP-10 Study**

The PhD study was nested within a larger AESOP-10 study. This study had two aims:

- 1) To identify the factors that predict the course and outcome of psychosis following a first-episode, focusing specifically on the role of biological and social risk indicators, cannabis use, and duration of untreated psychosis (DUP).
- 2) To study and explain the differences in the course and outcome of psychosis in Black and White patients in the decade following a first-episode.

The longitudinal follow-up study addressed these aims through a re-examination at eight to 12 years of an ethnically heterogeneous

epidemiologically-based cohort of 557 individuals who initially presented with their first-episode of psychosis between 1997 and 2000 in defined populations in South London and Nottingham and who took part in the baseline AESOP study. The sample comprised of all incident cases who presented to specialist mental health services within tightly defined catchment areas in the two centres (N = 532) and additional cases identified on an ad-hoc basis to supplement the MRI component of the baseline study in the London centre (N = 25).

#### **6.3.3.1 Tracing and re-contact procedures**

The procedures for tracing cases were in line with those used in previous long term follow-up studies of individuals with psychosis (e.g., Harrison et al., 2001; White et al., 2009). Patients recruited into the AESOP study at baseline provided the study team with their contact information including their current GP and relatives addresses. They also gave consent to be contacted at follow-up. The process for re-contacting current and past patients who took part in the baseline study happened in several stages:

- 1) contact with cases were currently in contact with mental health services was initially established.

For those who were, we sought to make contact and invite them to participate via their consultant psychiatrist and clinical teams. For those who were not,

- 2) letters were sent to their last known address with details about the study and inviting them to participate, enclosing a reply slip and stamped addressed envelope
- 3) Non-responders were sent a further letter two weeks later and, if necessary
- 4) researchers made a maximum of three visits to the address (morning, afternoon and evening) to make initial contact.

For those who had moved address (and for whom we had GP contact details),

- 5) Contact was sought via their GP and they were invited by letter to participate in the study. Letters were followed up where ever possible by a telephone call until initial contact was established. Non responders were sent 2 further invitations at one month intervals. Cases who had moved residence since baseline were traced through their original GP or consultant psychiatrist.

Towards the end of the study, a final check was conducted to determine whether any cases who at that point had not been traced had been re-referred to mental health services and, for any that had, we then sought to make contact via their clinical team, as above. Additionally, all deaths and emigrations were identified by a case-tracing procedure with the Office for National Statistics (ONS) for England and Wales and the General Register Office (GRO) for Scotland using name, sex, date of birth, and last known address of each case.

#### **6.3.3.2 AESOP Baseline Study**

During the AESOP baseline study, detailed information was collated from clinical records and interviews with cases and their relatives on clinical presentation (including mode of onset, duration of untreated psychosis, lifetime substance use, symptomatology, and diagnosis). Basic sociodemographic characteristics and detailed assessments were completed with cases on a range of biological, psychological and social risk factors (see Morgan et al., 2006). Baseline ICD-10 diagnoses were determined using data collected with the Schedules for Clinical Assessment in Neuropsychiatry (World Health Organisation, 1993 & 1994) (either from interview or from case records using the Item Group Checklist (IGC) part of the SCAN) on the basis of consensus meetings involving one of the principal investigators and other members of the research team.

### **6.3.3.3 AESOP-10 Follow-up data collection and study measures**

#### *Case Interviews*

Patients who were re-contacted (see above) were invited to take part in a face-to-face interview with the author or one of the AESOP-10 research team. The interviews involved several AESOP-10 assessments (see following sections) including the WHO Life Chart which most of the first phase of the PhD data was based on. Interviews were done over one, two or three visits depending on the availability of each individual case, the length of the WHO Life Chart Interview, and the number of additional AESOP-10 assessments the patient was willing to complete.

#### *Case Note Review*

Clinical records for all cases were also collected and data from these were used in addition to the interview data.

#### *WHO Life Chart*

Extensive information was collated across three course and outcome domains (clinical, social, and service use), first from clinical records and then, where possible, from corroborative follow-up interviews with cases and treating clinicians using an extended version of the WHO Life Chart.

The Life Chart has been used successfully in previous long term follow-up studies, including those with follow-up periods in excess of 10 years, and is designed to collate information from multiple sources. In the extended version the original Life Chart was adapted to include more items on substance use and service contacts and to include a timeline to document, month by month where possible, presence of psychotic symptoms and contacts with mental health services.

Following the approach adopted in other long term follow-up studies, in interviews with cases we used significant anchor dates (birthdays, births,

deaths, publicly significant events, etc.) to orientate subjects and assist recall and, as appropriate, interviews were structured around key events, such as hospital admissions. Using all available information, researchers reconstructed case histories over the follow-up period to complete all sections of the Life Chart. It has been shown that it is possible to obtain reliable ratings using the Life Chart (Susser et al., 2000), nevertheless, all clinical ratings in the Life Chart were made by consensus at weekly meetings (see below).

#### *Clinical Course, Outcome and Diagnosis*

Detailed information on clinical course and outcome was collected using the WHO Life Chart. In addition, information on current symptoms at follow-up (i.e. preceding month) was collected using the Schedules for Clinical Assessment in Neuropsychiatry (SCAN) Version 2, the Scale for the Assessment of Negative Symptoms (SANS), and the Global Assessment of Function (symptom score). Information from the Life Chart and SCAN were used to make a life time diagnosis for cases.

#### *Consensus Ratings and Diagnosis*

In line with the approach to diagnosis at AESOP baseline, a consensus approach to Life Chart clinical ratings and lifetime diagnosis was adopted. At weekly meetings involving at least one of the principal investigators involved at baseline and senior clinicians, researchers presented detailed summaries of the clinical symptomatology, course and outcome for each case based on information collated from clinical records and interviews with cases and other informants.

During these meetings consensus ratings of: a) variables relating to the occurrence and nature of psychotic episodes and substance use during the follow-up period, including month by month ratings of presence or absence of psychotic symptoms using the Life Chart timeline; and b) lifetime ICD-10 and DSM-IV diagnoses, were made. A conservative approach was adopted. The presence or absence of psychotic symptoms was only made if there was definite evidence. All ratings were made blind to the ethnicity of cases.

### *Primary Outcome of PhD study: Comorbid Substance Use disorder*

The data for quantitative PhD investigation relating to life time ever drug and/or alcohol use was collected using the WHO Life Chart. On the basis of information obtained, the presence or absence of a diagnosis of substance abuse or dependence (according to DSM-IV) was determined at consensus rating meetings. Patients were scored as having either

- No drug or alcohol use
- Sporadic drug taking (no evidence of regular use) or occasional social drinking
- Sporadic drug taking (suspected regular use) or moderate alcohol use
- Frequent or regular drug use or excessive alcohol use
- Drug or alcohol abuse
- Drug or alcohol dependence

The primary study outcome measure for the PhD study was a diagnosis of substance (drug and/or alcohol) use disorder. Substance use disorder was defined as having a diagnosis of drug or alcohol abuse and/or drug or alcohol dependence.

### *Ethnicity*

Ethnicity was assigned to patients during the AESOP baseline study. A number of data sources were used. The primary source was self-ascribed ethnicity (according to 2001 census categories), collected as part of the socio-demographic interview schedule. If this was not available other sources were used, including other informants and case notes. Where there was ambiguity, a consensus rating was made by members of the research team; this always included those with long-standing expertise in the study of ethnicity and mental health (Morgan et al., 2005).

### *Social Measures*

Information on sociodemographic markers of social function were collected (i.e. housing, employment, relationships, education and social

networks) during and at follow-up using the Life Chart. In addition other social function measures including the WHO Disability Assessment Schedule (DAS) and the GAF (disability score) were used. These measures were not used in the PhD study.

#### *Mental Health Service Use*

Detailed information on the nature and types of contacts with specialist mental health services as well as the prescription of and compliance with anti-psychotic medication throughout the follow-up was collected using the Life Chart. A timeline was used to document, month by month, contacts with services and to include detailed data on each hospital admission and community contact (i.e. dates of admission or contact, mode of contact, source of referral, reason for referral, and family and police involvement in pathway to contact).

#### *Other Assessments*

Additional assessments were conducted for those who agreed to be re-assessed at follow-up, including medication side effects, neurological soft signs, insight, neuropsychology were completed, and a proportion undertook follow up MRI scans. These were not included in the PhD study.

## **6.4 PHASE TWO: QUALITATIVE INVESTIGATION**

### **6.4.1 Sample**

#### **6.4.1.1 Theoretical and methodological issues around qualitative sample size**

Sample size is a contentious issue in qualitative research. Qualitative studies are not designed to be representative in terms of statistical generalisability (Pope et al., 2000), instead sample size should be determined by number of participants it takes to reach thematic saturation (Morse, 1995; Sandelowski, 1995). This however is problematic in itself when trying to set a target sample size during the



design phase of a study (Guest, Bunce & Johnson 2006). The sample size should also be influenced by the research question and analytical requirements (Pope et al., 2000).

The sample for Phase Two was taken from the AESOP-10 follow-up study sample. AESOP-10 started recruitment for the follow-up study in 2007 and data collection for the qualitative study began in the second half of 2008. The second qualitative arm of the PhD study used convenience sampling..

As we discussed in the previous section convenience sampling was used. Hammersley (1992) suggested that the combination of smaller sample qualitative research alongside survey research in the same investigation may be useful in increasing the generalisability of qualitative research. For Hammersley (1992) when the quantitative investigation comes first (as with this study) it may be used to inform participant selection decisions in the later qualitative phase. This was the case for the PhD study, where participants who took part in the first quantitative phase who were diagnosed with a diagnosis of comorbid substance use disorder were identified as eligible to take part in the second qualitative investigation.

In addition, (as suggested by Murphy et al., (1998) for multi-site research) quota sampling or stratified sampling (Patton, 1990) was used to increase the likelihood that the sample covers the range of variation which was found in the aggregate from which generalisation was sought (namely the AESOP-10 study). Participants were selected based on their ethnicity and gender to allow for differences between the four ethnic groups (Black Caribbean, Black African, White and Other), and genders to be explored. The key element of this type of sampling is selecting information-rich cases to study in detail (Patton, 1990).

After discussion with the AESOP-10 study co-ordinator who was experienced in qualitative research a target sample of thirty-two participants was set for the qualitative study. This would include eight

participants (four male and four female) in each of the four ethnic groups.

#### **6.4.1.2 Inclusion and exclusion criteria**

Differences in outcomes between current and past psychiatric patients without any substance use, with non-problematic substance use or diagnosable substance use disorders were explored in Phase One of the study. The second phase sampled cases with diagnosable substance abuse or dependence only to allow for detailed exploration of perceptions of illness, substance use, treatment and recovery in this group. For practical reasons only current and past patients that took part in the London study centre were sampled.

As part of the AESOP-10 study and first phase of the PhD study, data was collected from all cases relating to their clinical presentation, sociodemographic characteristics, and pathways into care. The patients sampled into the qualitative PhD study were included if:

- a) They took part in the London study centre of the AESOP baseline and AESOP 10 studies.
- b) They had a diagnosis (according to DSM-IV) of comorbid psychosis and substance abuse / dependence (F20-F29 and F30-F33 and co-occurring F10-19 in ICD-10 (WHO 1992).

In other words, they had to have scored at least a four on the WHO Life Chart in the AESOP-10 study.

Patients were excluded if:

- a) They refused consent to the AESOP or Quality of Care Study
- b) They were unable to be interviewed (e.g floridly psychotic and/or too unwell to consent to the study)

At the time of recruiting for the second phase of the PhD study only 170 patients had been followed up for the AESOP study. Of these cases 56 received a diagnosis of comorbid substance use disorder. Patients with a comorbid diagnosis were then assessed against the inclusion and exclusion criteria.

All eligible patients were grouped by their gender and self-ascribed ethnicity (Black Caribbean, Black African, White and Other) as recorded in the Culture and Identity Schedule I (CANDID I) (Mallet & Bhugra, 1996) for the AESOP study (see section 6.3.3.3). The aim was to obtain roughly equal numbers of male and female participants within each ethnic group. Once an ethnic quota had been fulfilled attention was paid to recruiting in other ethnic groups. This meant seven eligible patients in the White ethnic group were not approached to take part in the study and efforts to recruit respondents in the other ethnic groups was prioritised. Table 8 gives a summary of other patient exclusions and attrition.

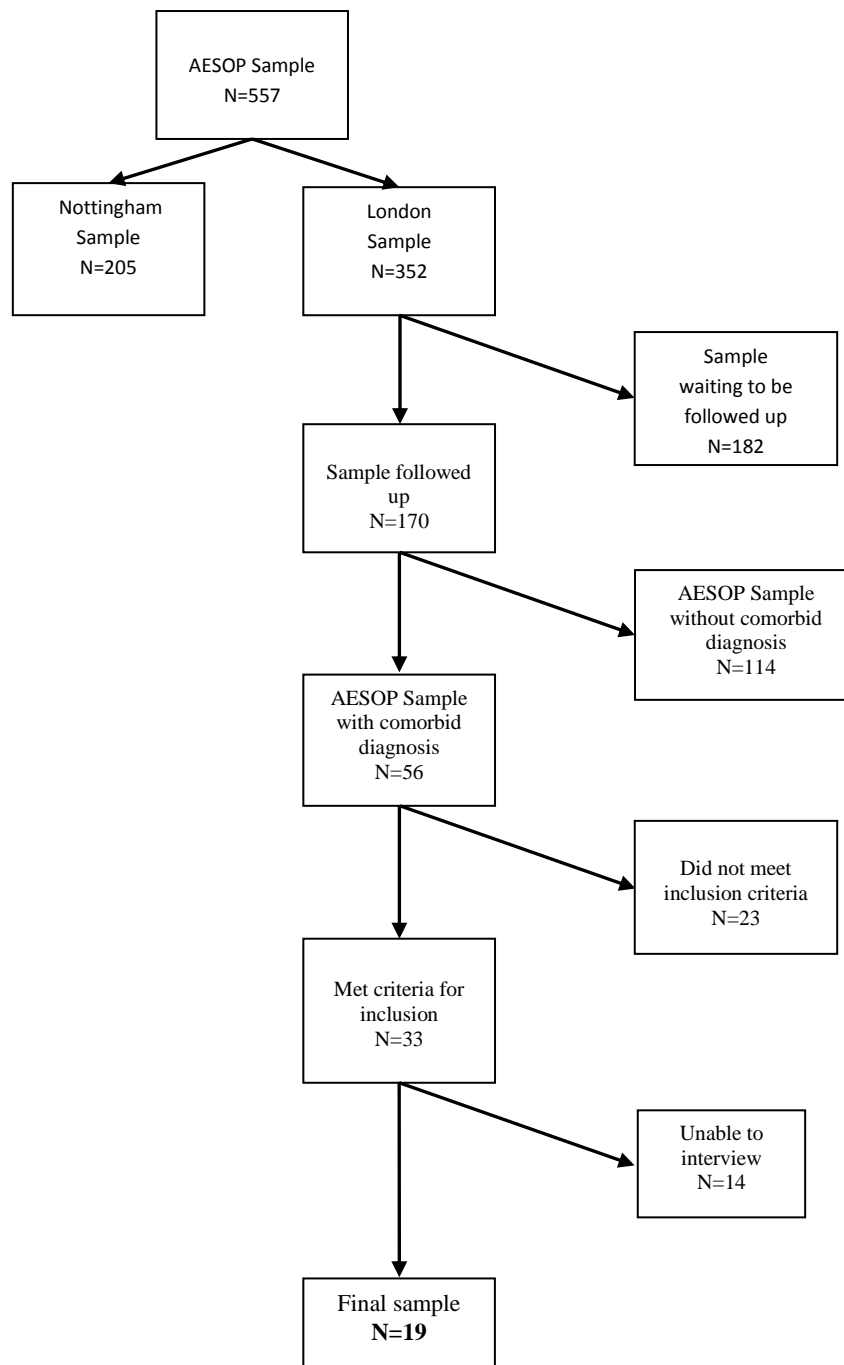
**Table 8: Summary of study sample exclusions**

<b><u>Reasons for exclusion/attrition</u></b>	<b>N</b>
<u>Exclusions</u>	
Refused consent to AESOP/QOC	15
Too unwell to interview	6
Deceased	2
<u>Unable to interview</u>	
Untraceable / Uncontactable	6
Declined Phase Two PhD Study	1
Not approached because reached ethnic quota	7
Total	37

This process resulted in a final sample (N=19) smaller than the target sample for this phase of the PhD. Figure 11 summarises the

process of obtaining the final sample. Section 8.2 compares the sociodemographic and clinical characteristics of patients that were excluded or defined as subject attrition to those who were included in the final sample.

**Figure 11: PhD Phase Two sample**



#### **6.4.1.3 Ethnicity**

The quantitative arm of the PhD study hypothesised that the prevalence of comorbid substance abuse / dependence in White and Black Caribbean ethnic groups will be higher than in Black African ethnic groups. The qualitative arm of the study however was interested in whether there were any differences in constructs of experiences between White, Black Caribbean and Black African and other ethnic groups of individuals with comorbid substance abuse or dependence. I have discussed in the previous chapters the way different ethnic groups perceive mental illness and why Black Caribbean, Black African and White groups were of particular interest in the study of psychosis aetiology and comorbidity epidemiology and perceptions of service use. Phase Two in addition to investigating perceptions of illness, substance use and treatment also sought to explore the complexity of participant's conceptions of their ethnicity and culture and thus critique the apparently neat boundaries of ethnicity as defined by the U.K Census.

#### **6.4.2 Methods and process for data collection**

##### **6.4.2.1 Recruitment**

In keeping with many sequential mixed method research studies, the second qualitative phase of this study was started after the AESOP-10 follow-up study and first phase of PhD study had begun. As the follow-up study had begun four years prior to the qualitative study, all cases who had been followed-up to the start date of the qualitative study had their Life Chart screened for eligibility. This produced an initial sampling frame of Fifty-six cases current and past psychiatric patients. This sampling frame was then subjected to further screening to exclude patients who didn't meet the inclusion criteria (see section 6.4.1.2).

Eligible patients who had completed all AESOP-10 assessments were contacted and an information sheet was sent to them. Those who

had not completed all their AESOP-10 assessments were given an information sheet or sent an invitation to participate in the Qualitative Study after completion of the AESOP-10 interviews. Invitations to participate were then followed up by a phone call from the PhD researcher whereby the study aims and objectives were explained in detail and the each person was given an opportunity to ask questions about the project. Patients were asked informally whether they would be happy to participate and a date was set to take consent and conduct the interviews. Separate informed consent was obtained for everyone participating in Phase Two interviews. All interviews were tape recorded and then transcribed for analysis.

#### **6.4.2.2 Interview setting**

The settings of the interviews were determined by each individual participant. Participants that were in contact with services were generally seen at the mental health team base or in hospital. For those that weren't in contact in services interviews were conducted either at the Institute of Psychiatry or in the person's home. Safety procedures were put in place for interviews conducted in the home. This included informing a member of the AESOP-10 research team of the interview date and start time and contacting them after the interview was completed.

#### **6.4.2.3 Phase Two topic guide for semi-structured interviews**

As current and past psychiatric patients participating in Phase Two will have participated in Phase One, data relating to psychiatric diagnosis, ethnicity, and the participants illness and service use timeline was available. This information was expanded on in the qualitative interviews, and detailed accounts of the participants' experiences of mental illness and drug/alcohol addiction as well as experiences of treatment services (both mental health and substance use disorder) was explored through

the use of a topic guide designed specifically for this study (see appendix 1). Broadly the areas that were investigated were:

- experiences leading up to and around first (and subsequent) contact with services for mental health problems;
- decisions to and/or processes of seeking help for substance use disorder problems;
- perceptions of and satisfaction with care received by treatment services (including treatment services ability to deal with comorbid problems);
- perceptions of usefulness of treatment in recovery/stabilisation of mental health and addiction;
- the role or perceived importance of family, friends or community support systems in engagement in treatment and recovery;
- the role or perceived importance of cultural awareness in mental health and substance treatment services; perceived areas in need of improvement in mental health and substance abuse treatment services.

The topic guide was piloted on the first two respondents to make sure that appropriate topics were covered and to refine the types of questions asked if needed. These first two interviews highlighted the need for more detailed exploration of ethnicity and its relationship with constructions of illness, substance use and treatment. With the first and second supervisors (who have expertise in qualitative research and constructions of ethnicity) of the PhD researcher the topic guide was then very slightly revised to include probing questions around self-definitions of ethnicity.

#### **6.4.2.4 Research diary**

As discussed in the last chapter there is a need for a reflexive approach to qualitative or mixed methods research. As part of this reflexive process a research diary was kept which included notes on

thoughts and feelings around the interview experience for each participant but also the PhD data collection process as a whole. The diary was not intended to be a primary source of data for the qualitative study, however it was used to jot down initial ideas for codes and categories as well as connected themes that might be uncovered during analyses.

### **6.4.3 Ethical considerations**

The AESOP-10 study obtained ethical approval from local ethics committees for the two study centres and all participants gave written informed consent to be interviewed. In addition separate ethical approval was sought from a local ethics committee for the qualitative study (see appendix 1 for ethical approval confirmation letter). As with the AESOP-10 interviews, informed consent was given by all respondents in the qualitative study.

Due to the sensitive nature of the topic great care was taken to emphasise to participants the confidentiality of the data collected during the course of AESOP-10 and qualitative interviews. Patients were reminded throughout the course of the interview that they did not have to respond to any questions they felt uncomfortable with or did not wish to answer. If patients became uncomfortable or distressed during the course of the interview the interviewer asked the participant if they wanted to take a break or stop the interview altogether.

A procedure was set so that if more problematic issues arose during the course of the interview possibly requiring action (e.g. participants disclosure of intent to harm oneself or others), then the interviewer would inform the PhD supervisors and/or consult one of the Consultant Psychiatrists who formed part of the AESOP research study team. All data collected for both phases of the PhD study were anonymised and held securely.



## **6.5 SUMMARY**

The PhD study is situated within a subtle realist position and combines, (using a sequential design, part explanatory part exploratory with both a deductive and inductive research process) a quantitative epidemiological study (Phase One) with a qualitative study (Phase Two). The study was nested within the larger MRC funded AESOP-10 (Aetiology and Ethnicity in Schizophrenia and Other Psychoses) follow-up study which looked at the course and outcome of psychosis in an ethnically diverse cohort of psychiatric patients. This study followed up patients who made contact with psychiatric services between 1997 and 2000 in two distinct geographical areas; South London and Nottingham.

The aims and objectives of the PhD study were to make a theoretical and methodological contribution to the understanding of the relationship between comorbidity of psychosis and substance use disorder and ethnicity. It also aimed to uncover patient perceptions of psychotic illness, substance use and service responses within different ethnic populations.

Several tracing processes previously used in other long term follow-up studies of individuals with psychosis were used in this study. In Phase One of the PhD study patients who were re-contacted were invited to take part in a face-to-face interview with the author or one of the AESOP-10 research team. The interviews involved several AESOP-10 assessments, including the WHO Life Chart which most of the first phase of the PhD data was based on.

The sample for Phase Two was also taken from the AESOP-10 follow-up study sample and used convenience sampling. Participants were selected based on their ethnicity and gender to allow for differences between the four ethnic groups (Black Caribbean, Black African, White and Other), and genders to be explored. Participants were invited to take part in an interview which used a semi structured interview topic guide. The setting within which the interviews took place varied from respondent to respondent.

As with all research involving NHS patients ethical approval for both phases of the study was obtained.

## Chapter Summary 6.

### Chapter Summary

#### Aims of the Chapter:

To provide a summary of the methodological structure and design of Phase One and Phase Two of the PhD study, including description of the sample population, study hypotheses and research questions, inclusion and exclusion criteria, method and process of data collection and measurement of study outcome.

#### Key Points:

- The PhD study is situated within a subtle realist philosophical stance
- The study is mixed method design including a quantitative epidemiological study (Phase One) and a qualitative study (Phase Two)
- A sequential, part explanatory part exploratory design is used with both a deductive and inductive research process
- Both phases of the study sample and use data from the AESOP-10 follow-up study
- To PhD study aimed to make a theoretical and methodological contribution to the understanding of the relationship between comorbidity of psychosis and substance use disorder and ethnicity.
- The study aimed to estimate the prevalence and correlates of comorbidity of psychosis and substance use disorder in different ethnic groups.
- The study also aimed to describe service responses to and explore perceived quality of care of patients with comorbid diagnoses from different ethnic populations, with special attention to Black Caribbean and Black African groups.

## **CHAPTER 7: ANALYTIC STRUCTURE OF THE STUDY**

The aim of this chapter is to both outline the analytic strategy for the PhD study for both the quantitative and qualitative stages and to link this to the epistemological stance of the PhD study. As discussed in the previous two chapters the design of the study was sequential mixed method. Data in these types of studies are often connected (connecting the analysis of results from the initial quantitative data collection with the data collection from the second qualitative phase of research). Preliminary analysis of the primary outcome in the first phase was used to inform the qualitative sample. Data from each study was then analysed separately (Chapters 8 and 9) but linked together in the discussion chapter (Chapter 10).

### **7.1 PHASE ONE – QUANTITATIVE INVESTIGATION**

#### **7.1.1 Summary of statistical analysis**

To address the first hypothesis chi-square ( $\chi^2$ ) tests were used to compare those with a comorbid substance use disorder, those who were users of substances and those without a history of substance use by ethnicity. Logistic regression analysis was used to estimate odds ratios for having a comorbid substance use disorder by ethnic group, while adjusting for potential confounders.

To address the second hypothesis, associations between sociodemographic, clinical and service use variables were investigated using chi square (categorical variables) or Kruskal Wallis (non-normally distributed count variables) tests as well as binary logistic regression, multinomial logistic, poisson regression and negative binomial.

Regression analyses allowed for main and interaction effects to be estimated, while adjusting for potential confounders.

Ethnic differences in the prevalence of psychosis were found between the two study centres in the baseline study (Morgan et al., 2006). In addition (as I discussed in Chapter 3) Mueser et al. (1992) found differences in the diagnosis of patients with comorbidity similar to those in normal psychotic pops where Black Caribbeans were more likely to have a diagnosis of schizophrenia. Accordingly psychiatric diagnosis and study centre were set as a priori confounders (alongside age and gender) and adjusted for in the phase one data analyses. Analysis was also stratified by study centre. All analyses were conducted using SPSS version 20.0 for windows (SPSS Inc., Chicago, IL, USA).

### **7.1.2 Study outcome variables**

The primary study outcome in the quantitative phase of this study was the prevalence of comorbid psychosis and substance use disorder. Data collected for this study outcome was used in part, to inform the sampling frame for the qualitative study. Comorbid drug and/or alcohol use disorder was defined by a score of 4 (abuse) or 5 (dependence) on the relevant sections of the WHO Life Chart.

Two (one for drug use and one for alcohol use) three level categorical variables were created and used as outcome variables to address the first hypothesis. A three-level variable separating drug users from non-users and those with use disorders was used for two reasons: drug users and non-users are likely to be characteristically different; and studies have shown mild and heavy substance use to have differing strengths of association with poor outcome (e.g. Linszen et al., 1994).

The second hypothesis aimed to investigate with the association between ethnicity, comorbidity and frequency of relapses over the follow-

up period and frequency of compulsory admissions over the follow-up period. Two count variables (number of psychotic episodes and number of compulsory admissions) created from data from the clinical and service use sections of the WHO Life Chart were used.

## **7.2 PHASE TWO – QUALITATIVE INVESTIGATION**

The second phase of the PhD study sampled patients with diagnosable substance abuse or dependence only to allow for detailed exploration of perceptions of illness, substance use, treatment and recovery in this group. This sample was generated from preliminary analysis of patient data (drug and alcohol use scores on the Life Chart and sociodemographic data including gender and ethnicity) from the London arm of the AESOP-10 study. Of the 56 patients eligible to take part in the qualitative study, 19 were interviewed. Below is a detailed summary of analytical process for Phase Two.

### **7.2.1 Analytical process**

#### *Field notes and Memos*

Grounded theorists have argued that a 'grounded theory' does not just rely on the interview transcript as a source of data (Corbin & Strauss, 1990). Strauss and Corbin (1990) also advocate the use of 'memos'. These are 'written forms of our abstract thinking about the data' (Strauss & Corbin, 1990, p. 198). Memos include notes about the data collection as well as notes on emerging theory. The importance of reflexivity in research particularly qualitative research has already been discussed. Field notes and memos are one way of being reflexive during the stages of data collection and analysis. Because participants were sampled from the AESOP study there was a possibility that they had already been interviewed before by the PhD researcher.

For some of the participants, prior knowledge about their psychiatric diagnosis at first contact with mental health services had already been obtained, including detailed knowledge of their symptomatology as well as any related personal experiences. This information was both a help and a hindrance to the interview. This knowledge could be used to ask salient questions or steer interviews in a particular direction because of preconceived ideas. For each interview field notes were made which included thoughts, impressions and information obtained from previous meetings with the respondents. This was to help make the data collection and analysis process transparent. Memos were used during all of the analysis stages but most frequently at the beginning of analysis. Memos are thoughts and ideas about the interview data and the researchers' own behaviour and thinking, and can be a good source of data in their own right (Dey, 1993). Memos were used to note inferences about what was being said in an interview transcript but also were re-read again to help form categories for the initial coding framework. They gave context to the data segments that were identified for categorisation.

#### *Codes, Categories and Themes: Developing the Initial Coding framework*

Reading is the foundation of qualitative data analysis. Dey (1993) has summarised various techniques for critical reading of data to help us categorise and subsequently form theory. How well we read (and annotate) our data can determine how well we analyse it (Dey, 1993, p. 83). In other words, to know what our data is telling us is in part dependent on how well (or how critically) we read it.

Secondly, it is useful to apply a varied approach to the reading. For example, attending to each word within each line of the interviews as well as the interviews as a whole. Dey (1993) outlines several methods for reading qualitative data, including free association (writing down all the images that come to mind when we read the data), shifting focus (e.g. looking at a transcript as a whole then looking at the detail of each line) and shifting sequence (i.e. reading the data in non-linear sequence).

In order to develop good familiarity with the interview transcripts as well as aid categorisation of the data several methods of reading were utilised in the analysis process.

Creating codes and categories are the next fundamental steps in the thematic analysis of interview transcripts (or any form of document analysis). Codes (words or phrases used to describe manifest content) are the starting point for creating categories and help us compare and contrast segments of data. A set of categories can then be built up and used as framework to help us analyse and make sense of large amounts of qualitative data, find links and connections between themes within and between respondent accounts and generate theory.

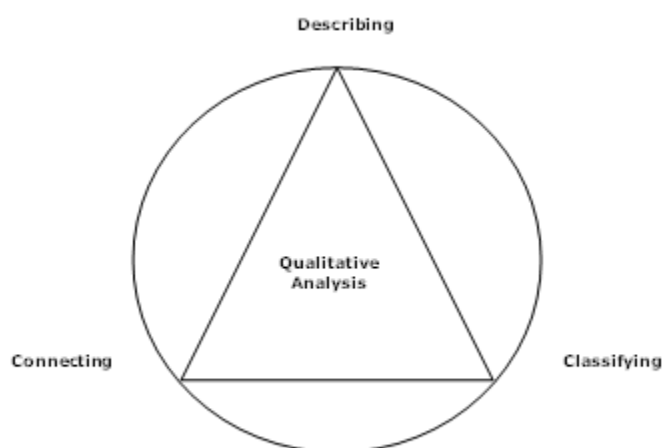
A 'category' is the collection of similar data sorted into the same place (Morse, 2008), or a group of content that shares a commonality (Krippendorff, 1980). Often the description of the characteristics (and consequently how the parameters of inclusion and exclusion are set) of a category happens alongside the identification of data segments that, at the start of analysis, loosely fit within it. Characterisation of the category then enables it to be compared and contrasted with other categories (Morse, 2008).

Often categories start broad and are 'split' (divided into sub-categories) or start narrow and are then 'spliced' with other categories (combined to become larger categories) (Dey, 1993). This type of categorisation formed the starting point for an initial coding framework for the analysis of the qualitative data. In-vivo coding (Crisp, 2000) was also used to identify terms used by respondents which evolved into more general categories or sub-categories at the later stages. Formal connections between categories (i.e. those that are characterised according to similarities and differences) as well as what Dey (1993) refers to as 'substantive' connections (e.g. connections that form the basis of causal explanations for events and experiences), were also uncovered.

As discussed in the preceding chapters the research process in reality is often deductive as well as inductive (Murphy et al., 1998) and this included the analytical process. Categories in qualitative analysis can be generated during the analysis process (i.e. inductive, theory generating and grounded in the data), as well as developed from a priori knowledge and influenced by literature in the area of investigation (deductive and theory testing). The approach to creating categories then becomes a circular one (see Figure 12).

It is true to say that in the development of the interview topic guide used to collect the data for this study, a priori themes (based on the researchers philosophical leanings and understanding of the study area, as well as key epidemiological and anthropological research) were considered, and these have influenced in part the categorisation of the data during the analysis stages. However, as much as possible the categories were developed from the data. The process of categorisation involves abstracting data segments from whole accounts and subsequently some meaning is lost. Qualitative analysis computer software is a useful tool for keeping records of information about the case and the original context each data segment comes from. Such information is vital to the interpretation of the data.

**Figure 12: Qualitative analysis as a circular process**



Adapted from Dey, 1993, p. 32.



Further along the analysis process categorisation leads to identifying themes within the data. As Bazeley (2009) has highlighted, the terms code, category and theme are often used interchangeably in qualitative data analysis literature. For clarity it is important then to distinguish between these terms as defined in this thesis. Codes have been described above. Categories here were considered to be collections of manifest data segments that share the same characteristics. Themes however were considered to be the latent meaning or 'essence' that runs through the data (Morse, 2008; Krippendorff, 1980; Downe-Wamboldt, 1992). Themes have multiple meanings; they answer the question 'How?' and are a way to link the underlying meanings of codes and categories (Graneheim & Lundman, 2003).

Baxter (1991) defines themes as threads of meaning that recur in domain after domain. It is useful in the analysis process and notably in theory generation to uncover categories as well as themes. Van Manen (1990, p. 87) has argued that the function of a theme is to 'describe an aspect of the structure of experience', and because themes tends to have multiple meanings they do not have to be mutually exclusive as we would often want categories to be. Once a set of categories (and their connections) had been identified they were sorted thematically into a list which formed an initial coding framework.

In Chapter 5 I discussed what the appropriate criteria for assessing qualitative and indeed mixed methodology were. The epistemological stance of subtle realism was identified as a means of framing mixed methodology designs as well as enabling the evaluation of conclusions made from mixed methodology research findings in terms of validity and relevance. However in order for this to be possible it is imperative that the process of data collection (as outlined in Chapter 6) as well as the process of analysis (as outlined here), be made transparent.

Several of the phases of qualitative analysis have been outlined above. However with the last point in mind, the step-by-step process of developing an initial coding framework for analysing the whole data set is

succinctly outlined below. These stages have been adapted from the steps for analysis of semi-structured interviews suggested by Smith (1995, pp. 19-22) and phases of thematic analysis in psychological qualitative research suggested by Braun and Clarke (2006, p. 87) and were used by the author and co-coders (discussed below):

1. Read in detail and several times, 3 interview transcripts picked at random
2. Generate annotations (i.e. memos of initial ideas about the data) on each transcript and note these in a margin to the side of the transcript (or using a computer based analysis package).
3. In another margin down the other side of the transcript (or using a computer based analysis package) note down emerging codes and categories.
4. Collate categories looking for connections between them, sort them into potential themes, give each theme a code/categorical name and order them in a coherent list.
5. Revisit the transcripts gather all data relevant to each potential category and theme.
6. Collate, compare and contrast category and theme lists from all coders
7. Check if the themes work in relation to the coded extracts and sub-sample of transcripts as a whole, producing new categories and themes that emerge and re-arrange the thematic list where necessary.
8. Keep refining the specifics of each theme and category, and the overall story the analysis tells, generating clearer definitions and names for each theme/category using the raw data.
9. Produce a final coding framework

Below is an illustration of the process of assigning codes, categories and themes. It also shows how memos were used to remind the author to think critically about the data and to navigate them to other categories and themes.

In this illustration it is possible to see how data segments are extracted and put into categories according to their manifest meaning. The category 'psychiatric terms' is self explanatory and forms part of a larger category called 'Terminology & Signs' which is a collection of terms used by the respondents to describe their experiences as well as larger data segments which point to signs or views of what 'mental illness' is. This category could be kept as it is or turned into a categorical variable to show differences between respondents that tended to use psychiatric terms and those who tended to use lay terms to describe their experiences.

Initially three other categories were found; 'previous knowledge' (previous knowledge about mental illness in general or their own mental illness); 'Not given enough info' (examples of when the respondent felt they weren't given any or enough information about their experiences/mental illness by hospital or community staff); and 'Finding out info yourself' (examples where respondents have researched their own experiences/mental illness). When these categories were looked at together a relationship between them was found. They all relate to how much a respondent understands about mental illness or their experiences.

**Figure 13: Assigning codes, categories and themes**

Data		Sub-category Code	Category Code	Theme Code
Interviewer:	Did anyone come and talk to you about why you were there – like, what was happening to you?			
Respondent:	<p>Yes. They must have explained that this bi-polar, but it was all new to me. I had never heard of it. I had heard of schizophrenia and all other things but I had never heard of manic depression as they called it then.</p> <p>So....I don't know. I don't think anyone came and explained it to me. They must have said: "You have mood swings and you get high, you get low". They always talk about a swing, and you swing from side to side. Yes. That was about it. Nothing more than that. It was only later, when I was in [the service] a bit longer and I started doing research and things like that – that's when I got to know the effects of it and things like that..</p>	<p>Psychiatric terms</p> <p>Previous knowledge</p> <p>Not given enough info</p> <p>Finding out info yourself</p>	<p>Terminology &amp; Signs</p> <p>Understanding illness</p>	<p>MEMO: Inconsistency in account; yes info given and no info given. Look at language, 'they must have..'. Related to recall</p> <p>Mastery &amp; Involvement</p>

When the rest of the account was scrutinised in this way it was found that 'Understanding illness' formed part of a theme running through the whole account which related to the amount of control and command a person felt they had over their experiences including the amount of involvement they had in their treatment experiences.

This theme was based on more latent content in the data. The memo that was made for this data segment asked the author to be mindful of the inconsistency in this data segment (and thus its reliability). It also sent the author back to look at other categories that were made around recall ('remembering') which formed part of a larger theme called 'account devices' (ways of giving an account or creating shared meaning, possibility related to social desirability). This in turn may lead to this data segment being used in another category or just highlight more what is going on in the data segment.

#### *Enumerating responses, identifying typologies and the importance of A-typical cases*

Part of qualitative analysis is uncovering patterns in the data. Dey (1993) advocates the use of quasi-statistical methods in qualitative analysis to help with this. Qualitative computer analysis packages are really useful for this. They allow crude categorical variables to be created from codes used to describe categories and themes.

These variables can then be analysed statistically and used to generate frequencies and even to cross-tabulate categorical variables with sample characteristics. This enables the identification of variations or confirmation of regularities, as well helping to explore connections within the data (Dey, 1993). It is this process that allowed comparisons to be made in the qualitative study between genders and the different ethnic groups, but also those with different types of addiction and between respondents who constructed different relationships between their mental health and drug use. This formed the basis of identifying typologies within the data.

One way to increase the reliability and validity of interpretation and theorising in the analysis process is by using atypical or negative cases (Miles & Huberman, 1994). These are essentially exceptions to the rules or characteristics used to set the boundaries of a category or theme. Searching for these exceptions helps the researcher avoid the temptation to only look for evidence that confirms their views or theories (Dey, 1993). They can also help redefine the boundaries of categories and themes as well as explain what is going on in larger samples (Bazeley, 2009). As part of the analysis process for the qualitative study negative cases were sought out and included in the reporting of the findings.

#### *Thematic analysis: Generating theory*

In grounded theory research generating theory is the ultimate goal. Although this thesis does not fall within the definition of grounded theory research, generating theory was a primary aim. I have outlined above the process of creating an initial coding framework for analysing the whole sample of accounts, as well as the role enumeration, creating typologies and examining negative cases played in the analysis process. The last stage of the analysis process as outlined by Braun and Clarke (2006) is the selection and analysis of compelling extracts which are then related back to the research question and background literature. However we need to see whether we have created a coherent and 'sound' model or theory from the data.

Enumeration, typologies and examination of negative cases all form part of this process, but it is useful to outline some of the steps or better 'criteria' which signify theory generation and were used to guide the more detailed and final stages of data analysis in this study. These three steps are adapted from suggestions by Pat Bazeley (2009) and referred to as 'moving from garden path analyses'. Some of the processes described can be found in the earlier analysis steps described

above while others were reserved for the reporting of the results. Each step (repeated for each theme) is outlined below:

- **Describe.**

Outline the context for the study and provide details about sources of data (demographics and characteristics of the sample). Describe the interrelationships between these characteristics which give background to the data and form the basis of comparative analysis. Move on to the first major category or 'theme', describing its characteristics and boundaries. Ask questions like; how did people talk about this aspect, and how many talked about it? What's not included?

- **Compare**

Look at differences in the characteristics and boundaries for each category or theme, contrasting between demographic groups or across variations in context. Ask questions like: Do themes occur more or less frequently for different groups? Are they expressed differently by different groups? Report meaningful associations as well as the absence of associations.

- **Relate**

Relate each category or theme to others already written about. Ask more questions like: Under what conditions does this category or theme arise? What actions/interactions/strategies are involved? What are the consequences and do these vary depending on the particular circumstances or the form in which it is expressed?

As Bazeley highlights: 'As you describe, compare and relate for each element with an enquiring mind and an eye for evidence, your picture will become increasingly complex and your theory or thesis will develop, building on the foundation you have laid. Your analysis, then, will come together around an integrating idea, with arguments to support it drawn from across your completed (interim) analyses.' (Bazeley, 2009, p. 10).

### **7.2.2 Reliability, validity and multiple coders**

Although issues around reliability and validity of data analysis imply one single truth (in philosophical terms), there is still a need to increase the likelihood that interpretation of data is representative of the account giver, study sample and if possible population of interest. The interviewer has influence over both the data generation (the instruments used and the interview itself) and data analyses.

Various considerations were given during data analysis and interpretation including the possible indirect influence interviewer characteristics may have had on accounts elicited as well as the context in which interviews were conducted (for example treatment or clinical settings vs. community or home settings).

It would be true to say that commissioners of research look at processes and procedures that constitute 'good' qualitative research (Barbour, 2001). Having two (or more) primary coders has been considered one way of producing 'good' qualitative research (Berends & Johnston, 2005). Barbour (2001) has argued that the benefits of multiple coders can be found in the content of agreement and disagreement in codings and that discussions between coders about their 'choices' of data segments can provide insights and help to refine coding frameworks.

Three coders were used to produce the initial coding framework. The primary coder was the author and the two other coders were PhD students in the authors department. Each coder coded between 1 and 3 transcripts (using the process for creating the initial framework above) and once an initial list of categories and themes had been generated these were then compared and contrasted in a consensus meeting.



Although evaluative criteria such as inter-rater reliability (which assumes one single truth) are not appropriate for qualitative research, it is useful to detail some of the agreements and disagreements between the co-coders and how these were resolved.

**Table 9: Summary of the process of agreeing a final coding framework for the Qualitative Study**

Theme/Category/Code	Coder 1	Coder 2	Coder 3	Coding Agreement
<b>Treatment and Recovery</b>	<ul style="list-style-type: none"> <li>➤ The benefits of hospitalisation <ul style="list-style-type: none"> <li>▪ Change in thinking</li> <li>▪ Change in mood</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>➤ Involvement vs. being done to – passivity vs. agency, contradictions and consistencies</li> <li>➤ Perceived reasons for admittance</li> <li>➤ Frustration</li> <li>➤ Impact of treatment vs. impact of hospitalisation</li> <li>➤ Staff as friends/allies/enemies</li> <li>➤ Dissociation from other patients – patients as ‘other’, special</li> <li>➤ Playing the game, acting out</li> <li>➤ Inside vs. outside</li> <li>➤ Leaving/re-entering community</li> <li>➤ Post-discharge care and continuity</li> </ul>	<ul style="list-style-type: none"> <li>➤ Treatment and Recovery</li> <li>➤ What (what type of treatment is useful)</li> <li>➤ Where (where should it be provided) <ul style="list-style-type: none"> <li>▪ Hospital</li> <li>▪ Community</li> <li>▪ Home</li> </ul> </li> <li>➤ positive experience / negative experiences</li> <li>➤ Definition (what was treatment defined as i.e. the provider) <ul style="list-style-type: none"> <li>▪ Treatment services</li> <li>▪ Family support (recognising the person is ill, taking them to the hospital, having someone to talk to / care for you)</li> </ul> </li> <li>➤ Responsibility <ul style="list-style-type: none"> <li>▪ Active / passive participation</li> </ul> </li> <li>➤ Emotional / psychological experiences <ul style="list-style-type: none"> <li>▪ Personality change</li> <li>▪ Mood change</li> </ul> </li> </ul>	<p><b>Yes (separation of hospitalisation, treatment and recovery and active/passive involvement themes)</b></p> <p>*Hospitalisation theme to include: usefulness of being in hospital; transition of care to community services or discharge home; experiences inside hospital compared to outside hospital; behaviour on ward; frustration; view of other patients;</p> <p>*Active and passive involvement in treatment theme.</p> <p>*Treatment and Recovery theme to include: what type of treatment; where should treatment take place; who should treat.</p>
<b>Symptoms and illness experiences</b>	<ul style="list-style-type: none"> <li>➤ Recognising symptoms</li> <li>➤ The benefits of hospitalisation <ul style="list-style-type: none"> <li>▪ Change in mood</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>➤ External vs. internal origin – ‘it was happening to me’</li> <li>➤ Description of symptoms as psychosis, mentally ill? Proper psychosis?</li> <li>➤ Attribution of cause – external vs. internal</li> </ul>	<ul style="list-style-type: none"> <li>➤ Defining the experiences</li> <li>➤ Terms (psychiatric vs. lay)</li> <li>➤ Definitions / conceptualisations (physical vs. behavioural) <ul style="list-style-type: none"> <li>▪ Acting out (on purpose as opposed to not being able to help the way you behave)</li> </ul> </li> <li>➤ Emotional / psychological experiences <ul style="list-style-type: none"> <li>▪ Personality change</li> <li>▪ Mood change</li> </ul> </li> <li>➤ Symptoms</li> </ul>	<p><b>Yes</b></p> <p>*Constructions of symptomatology as a theme to include: understanding and recognising your own illness symptoms; defining symptoms; type of symptom; attribution of cause of symptoms; changes in symptoms</p>

Theme/Category/Code	Coder 1	Coder 2	Coder 3	Coding Agreement
<b>Drug use and mental health relationship</b>	<ul style="list-style-type: none"> <li>➤ Is drug use separate from mental health?</li> </ul>	<ul style="list-style-type: none"> <li>➤ Effects of drug use on self (mental/physical/practical)</li> <li>➤ Perceived link to episode/MH</li> </ul>	<ul style="list-style-type: none"> <li>➤ Related to my illness / not related to my illness</li> </ul>	<p><b>Yes</b></p> <p>*Drug use related to my experiences theme. Use this theme as a categorical variable.</p>
<b>Risk Factors</b>	<ul style="list-style-type: none"> <li>➤ Living context theme <ul style="list-style-type: none"> <li>▪ relates to risk factors (low education, homeless, ethnicity)</li> </ul> </li> </ul>	N/A	N/A	<p><b>No</b></p> <p>Risk factors were not directly elicited in accounts. This relates to psychiatric models not lay models. Is not clearly constructed.</p>
<b>Coping</b>	<ul style="list-style-type: none"> <li>➤ Coping</li> </ul>	<ul style="list-style-type: none"> <li>➤ Coping and drug use</li> </ul>	N/A	<p><b>Yes</b></p> <p>*Coping theme to include: general coping; constructions of drug use as a coping mechanism.</p>
<b>Locus of Control/ Responsibility/Cause: (internal vs. external)</b>	N/A	<ul style="list-style-type: none"> <li>➤ Symptoms <ul style="list-style-type: none"> <li>▪ External vs. internal origin – ‘it was happening to me’</li> <li>▪ Attribution of cause – external vs. internal</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>➤ Causes of the experiences <ul style="list-style-type: none"> <li>▪ Located in wider society (responsibility with other)</li> <li>▪ Located in immediate social setting (responsibility with other)</li> <li>▪ Located in individual (responsibility with self)</li> </ul> </li> </ul>	<p><b>Unsure</b></p> <p>Confusion of concepts (LOC and responsibility). LOC constructs not clearly elicited in accounts. This theme needs further development.</p>

The above Table (Table 9) summarises an example of the process in which several themes and categories were agreed between the three co-coders for the final coding framework. Many themes identified in the individual coder's preliminary coding frameworks were similar and featured in the combined framework (e.g. the relationship between drug use and mental illness experiences). Other themes were either only present in one or two of the preliminary coding frameworks or differences in the description or categorisation of the theme were apparent. A theme was included in the combined coding framework if at least two coders had highlighted it. For example, the theme relating to 'coping' was highlighted in only coder 1 and coder 2's frameworks.

However some themes required splitting or splicing even when there was agreement. For example all three coders highlighted constructions of treatment and recovery in the accounts they coded. Coder 1 focused primarily on the individual patient's cognition and emotional states, coder 2 uncovered constructions of patients perceptions of treatment, interactions with other patients, involvement in treatment and experiences when not in treatment, while coder 3 focused on the details of treatment agencies, the patients and significant others involvement and the patients emotional states. However all three coders highlighted the distinct relevance of the experience of hospitalisation. Subsequently the theme 'treatment and recovery' was split into three different categories:

- Hospitalisation
- Active and passive involvement in treatment and
- Treatment and Recovery.

Some themes identified by the three coders were not included in the combined coding framework. For example, two of the coders highlighted themes of control and responsibility. On further discussion these concepts were considered separate. Clear constructions falling within Rotter's (1954) concept of 'locus of control' (internalisation and externalisation), were not clearly elicited in the transcripts. Constructions of causes were elicited, however these constructions were more closely

framed within understanding rather than control. Instead, themes of power and control in the treatment process rather than external and internal attribution of causes were more clearly prominent in accounts. This theme was omitted in its initial form from the combined framework however after further analysis it was revisited, redeveloped and included as the account giving mechanism 'apportioning responsibility'.

As highlighted in the chapter sub section detailing the process of developing the initial coding frameworks, each coder analysed the data using a nine-step process. However, as is often the case with qualitative data analysis the process of checking if the themes in the coding framework worked in relation to a sub-sample of transcripts resulted in producing new categories and themes, as well as refinement of initial categories (steps 7 through to 9).

This meant that the combined coding framework generated from the consensus meetings with the three co-coders was subject to additional changes when the PhD author tested it against other interview transcripts. For example the theme concerning symptomatology was adapted further after additional analysis of the interview transcripts to include sub themes which reflected the different ways in which a symptom could be experienced (i.e through feelings, thoughts or behaviours).

Although the author was responsible for creating a final coding framework (see appendix 4 for summary of the three initial coding frameworks of individual coders, as well as the final coding framework), which was the applied to the rest of the sample, these considerations helped enable independent judgement of the conclusions to be drawn.

### 7.3 THEORETICAL CONSIDERATIONS

It is important to discuss the philosophical assumptions underpinning the analysis of the PhD study data. I have discussed the framework within which the PhD study is situated and it is this 'middle ground' theoretical stance that also frames the analytical approach to the study.. In other words, the analytical structure of the study is also bound by the same ontological and epistemological understandings as its method. Approaches to data analyses need to either share the same theoretical understandings of the overall design of the study or use analytical methods that allow for the studies philosophical standpoint to be embraced. It should be noted that Subtle Realism is not a methodological or analytical approach in its own right like the commonly used Grounded Theory.

Similar to the 'grounded theory' approach of Glaser and Strauss (1967) and Strauss and Corbin (1990) however, the analytical structure for the qualitative phase of the PhD study is based upon on a variety of different strategies for 'coding' or 'categorising' data and generating theory that is grounded. It would be true to say that thematic analysis has been considered the corner stone of GT research (Ryan & Bernard, 2000). Some of the reasons as to why the research here despite assuming many of the methodological techniques used in Grounded Theory (GT) (creating codes and categories, using memoing techniques during data collection and analysis, constant comparison in the analysis process and going beyond description and generating theory which is grounded in the data) cannot be classed as a piece of grounded theory research have been outlined by Becker (1993) in *Common Pitfalls in Published Grounded Theory Research*.

Here Becker describes several obstacles which researchers claiming to use GT find themselves having to overcome including using narrative rather than theoretical approaches to data collection and analysis, using selective as opposed to theoretical sampling as well as making sure they use a true constant comparative method. She also points as Milliken and

Schreiber (2012) have, to the importance of seeing the research project through the correct 'theoretical lens' namely Social Interactionism. It can be argued however that these elements of GT which are essential in creating a true piece of GT research, are arguably the backbone of how to do 'good' GT and possibly represent the 'rigor' part of the GT research process.

In addition the question as to whether it is theoretically appropriate to use elements of GT in the research process (and by virtue using techniques which are informed by social interaction) while aligning the study to a completely different epistemological stance should also be considered? Milliken and Shreiber (2012) refute in the possibility of conducting a piece of a grounded theory research without social or symbolic interactionism. They argue that 'the ontology, epistemology, method, and techniques of grounded theory are all steeped in symbolic interactionism, such that the two cannot be divorced' (Milken & Schreiber, 2012). They also argue that grounded theory is more than a sum of techniques.

However it is also arguable that there are individual techniques associated with GT which could be used more freely (i.e. they have more philosophical flexibility). So can methods be epistemologically naïve and subsequently aligned to virtually any methodological or epistemological positions? Although there are data collection and analytical methods which do have clear philosophical leanings, some qualitative researchers have argued (including Milken & Shreiber themselves) that many methods and techniques are more closely linked with practical concerns (Silverman, 2013).

Similarly, Bryman (1988, p. 124) has argued that research methods are probably much more autonomous and adaptable than some epistemologists would like to believe, and Braun and Clarke consider thematic analysis (the foundation of GT analysis) to be flexible enough to accommodate both realist and constructionist (or Idealist) research (2006).

Many of the qualitative analytical techniques described in this chapter have been advocated by Ian Dey. Indeed Dey (1993) argues that 'practical problems of conceptualizing meanings are common to a range of different perspectives'. In his book *Qualitative data analysis: A user-friendly guide for social scientist* he describes how interpretive approaches (e.g. Patton, 1980) have emphasised the role of creating patterns, categories and using basic description. He also outlines how the Network approach used by Bliss et al. (1983) equally focuses on categorisation, and Miles and Huberman (1984) have advocated the use of quasi-statistical approaches in qualitative analysis ('pattern coding') (Dey, 1993).

From a similar standpoint as above I would argue that the qualitative analytical techniques used in the PhD study (those that could be considered elements of grounded theory) are methods that could be considered 'good' practice in producing reliable and valid qualitative research and are flexible enough to be used within a non-Social Interactionist framework. In other words, the qualitative phase of this study is not simply using elements of GT but using methodological and analytical techniques that have formed part of GT research but also have flexibility to be used in research subsumed by subtle realist philosophy.

The assumptions underpinning the epistemological stance and methodological approach to the PhD study are firstly that, data collection and analytical methods can be seen as tools in a tool-kit (as described in Chapter 5) and secondly, that the analytical techniques (as with the methodological techniques) used in both phases of the PhD study make sense within and can be framed by the studies ontology.

The ontology and epistemology of Subtle Realism acknowledges the existence of an independent reality (i.e. that comorbid psychosis and substance use disorders exist as a health condition), and a world that has an existence independent of our perception of it, but it also assumes that there cannot be direct access to that reality (through quantitative or



qualitative methods). The emphasise instead, is on representation not reproduction of social phenomena. This representation can be achieved through enumeration and statistical testing as well as through account giving and thematic constructions.

As noted by Andrews (2012), representation of reality implies that it will be from the perspective of the researcher, thereby implicitly acknowledging reflexivity, which is acknowledgement that researchers influence the research process. This could, for example, be the choices made when creating variables, choosing confounders and statistical test in quantitative research as well as the question choices made when conducting semi-structured interviews as well as the codes and categories created in thematic analysis).

The question as I have argued in the previous chapters is do these techniques 'get the job done'? It is in this very process of trying to answer the above question that mixed methodology has been made possible. It is not a case of ignoring epistemology altogether rather embracing conflicting epistemology or as in the case of subtle and perhaps critical realism combining a realist ontology with a constructivist epistemology.

## **7.4 SUMMARY**

To address the study hypothesis in Phase One of the PhD study various statistical methods were used including chi-square ( $\chi^2$ ) tests; Kruskal Wallis tests; and regression analyses. The primary study outcome and variable of interest in the quantitative phase of this study was the prevalence of comorbid psychosis and substance use disorder (drug or alcohol). Data collected for this study outcome was used in part, to inform the sampling frame for the qualitative study.

Along with the interview transcripts themselves, field notes and memos were used to help construct codes, categories and themes within the qualitative data. A varied approach to 'reading the data' formed the preliminary stages of data analyses. The categories and themes generated from analysis of respondent's interviews formed the basis for identifying typologies within the data. Thematic analysis techniques were used for analysing the qualitative data. This analytical method was chosen for its philosophical naivety and subsequent compatibility with a subtle realist perspective.

Three qualitative coders were used to create a coding framework from which the whole data would be analysed. Enumeration, creating typologies and examination of negative cases all form part of this process of theory generation.

The assumptions underpinning the epistemological stance and methodological approach to the PhD study were that, data collection and analytical methods can be viewed as tools in a tool-kit.

## Chapter Summary 7.

Chapter Summary
<p><u>Aims of the Chapter:</u></p> <p>To outline the analytic strategy the PhD study used to address its aims and objectives. To link this to the epistemological stance of the PhD study.</p> <p><u>Key Points:</u></p> <ul style="list-style-type: none"> <li>• Approaches to data analyses need to either share the same theoretical understandings of the overall design of the study or use analytical methods that allow for the studies philosophical standpoint to be embraced.</li> <li>• Various statistical analysis methods were used to address the study hypotheses in the first phase of the PhD study.</li> <li>• Thematic analysis is considered a technique, and was chosen as the method for analysing the qualitative study data because of its compatibility with a subtle realist perspective.</li> <li>• Co-coders were used in the qualitative analyses process</li> <li>• Theory generation was attempted through enumeration, creation of typologies and examination of negative cases</li> <li>• Data from each phase of the study was analysed separately but linked together in the discussion chapter (Chapter 10).</li> </ul>

## **CHAPTER 8: PHASE ONE RESULTS**

The quantitative study design, including details of the study assessments, has been discussed in Chapter 6 and the analytical framework for the quantitative arm of the PhD study, including the overall method of statistical analyses, has been discussed in Chapter 7.

This chapter aims to summarise the findings from the quantitative arm of the PhD study. In line with the study hypotheses it will examine firstly the ethnic differences in the prevalence of comorbid drug (DUD) and alcohol (AUD) use disorders in a sub-sample of the larger Aetiological study AESOP; with particular attention to whether comorbid substance use disorders (SUD) are more likely in Black Caribbean groups and less likely in Black African groups compared to Whites. The chapter will then examine whether regardless of ethnic group comorbidity was associated with the frequency of psychotic relapse and compulsory hospital admissions over the follow-up period.

### **8.1 SOCIODEMOGRAPHIC AND CLINICAL VARIABLES**

The main study outcome was comorbid substance use disorders which included drug use disorders and alcohol use disorders. These two types of substance use disorder were analysed separately.

As discussed in section 6.3.3.3 substance use over the follow-up was measured using the WHO Life Chart. Drug use was categorised in six ways (no drug use; sporadic drug taking, no regular use; sporadic drug taking, possible frequent or regular use; frequent or regular use definitely present; drug abuse; drug dependence). Comorbid drug use disorder was defined as having either drug abuse or drug dependence. Alcohol use was also categorised in six ways (no alcohol use; only occasional social

drinking; moderate alcohol use; excessive alcohol use; alcohol abuse; alcohol dependence). Comorbid alcohol use disorder was defined as having either alcohol abuse or alcohol dependence. Any type of non-abusive or non-dependent drug use was grouped together and a three-level categorical comorbid drug use disorder variable was created (no drug use; drug use; comorbid drug use disorder). The same was done for alcohol use.

Other sociodemographic and clinical data from the AESOP follow-up study (see Chapter 6 for the method for data collection) were used in the PhD study analysis and the following variables were created:

- Ethnicity: this was a three-level categorical variable (White British, Black Caribbean and Black African).
- Gender: Males and females.
- Age at first contact with mental health services: this variable was dichotomised (16-29 years and 30+ years) in accordance with the BCS.
- Diagnosis: ICD-10 and DSM-IV diagnosis were generated for each patient (see section 6.3), however for the purposes of these analyses the variable for diagnosis was split into a three-level categorical variable: non-affective psychosis (including schizophrenia, schizoaffective, substance related psychosis, delusional disorder, acute psychotic disorder and other non-affective psychosis), manic and depressive psychosis.
- Study centre: Nottingham and South East London.
- Course type: The type of illness course each patient experiences was categorised into five groups (Episodic - Continuous, primarily positive symptoms; Continuous, primarily negative symptoms; Continuous, primarily symptoms positive and negative symptoms; Neither episodic nor continuous). For the purpose of data analysis in this investigation the 'Continuous' groups were collapsed into one category and a new three-level variable was created (Episodic, Continuous and Neither).

- Compulsory admission; a new binary variable for whether a patient had experienced a compulsory admission or not was created for all patients that had had at least one hospital admission over the follow-up.

## **8.2 SAMPLE CHARACTERISTICS**

The total AESOP sample was 557. Data was collected for all ethnic groups but, as mentioned above, the PhD study was only concerned with patients from White, Black Caribbean and Black African ethnic groups, so all patients not belonging to those groups were also excluded (N=99) leaving an eligible sample of 458. As mentioned in section 6.3.1 information was limited for patients with a follow-up of less than eight years and because of patients who had died or moved abroad, the following analyses for this study involved only patients who had at least eight years of follow-up, meaning there was a final sample of 325.

A subsequent power analysis calculation was performed to estimate the study power after data collection. Looking at prevalence of comorbid alcohol use disorders (AUD), tests with a 0.05 two-sided significance level were found to have 98% power to detect the difference between White patients (Group 1) with 64% prevalence of comorbid AUD and Black African patients (Group 2) with 14% prevalence of comorbid AUD (unadjusted odds ratio of 0.093) when the sample sizes were 42 and 21, respectively (a total sample size of 63, which included those with no alcohol use and those with comorbid AUD).

Table 10 compares the sample characteristics of eligible patients included (those with at least eight years of follow-up data) and excluded (those with less than eight years of follow-up data) from the analysis for the three ethnic groups of interest. Chi square analyses were used to explore differences on primary sociodemographic and clinical variables at baseline for the two groups for each study centre. Numbers in the Black

Caribbean and Black African groups for Nottingham were too small to make comparisons between those included and excluded.

There were significant differences in the gender of those with at least eight years of follow-up and those without, with slightly more females in the included sample for the London centre ( $\chi^2 = 7.979$ , d.f.=1,  $p=0.05$ ). There were also significant differences in ethnicity between the two groups in the London centre, with slightly more Black Caribbeans in the included sample ( $\chi^2 = 6.337$ , d.f.=2,  $p=0.042$ ). This difference was only just significant however.

**Table 10: Comparison of included and excluded cases by study centre**

	London				Nottingham			
	Included N (%)	Excluded N (%)	$\chi^2$ (d.f.)	<i>P</i>	Included N (%)	Excluded N (%)	$\chi^2$ (d.f.)	<i>P</i>
Gender <sup>a</sup>								
Male	101 (52.6)	64 (70.3)	7.979	0.005	77 (57.9)	24 (66.7)	0.907	0.341
Female	91 (47.4)	27 (29.7)	(1)		56 (42.1)	12 (33.3)	(1)	
Age <sup>a</sup>								
16-29	104 (54.2)	54 (59.3)	0.670	0.413	67 (50.4)	21 (58.3)	0.719	0.397
30 yrs and over	88 (45.8)	37 (40.7)	(1)		66 (49.6)	15 (41.7)	(2)	
Ethnicity <sup>a</sup>								
White	52 (27.1)	36 (39.6)	6.337 (2)	0.042	118 (88.7)	33 (91.7)	-	-
Black Caribbean	94 (49.0)	31 (34.1)			14 (10.5)	2 (5.6)		
Black African	46 (24.0)	24 (26.4)			1 (0.8)	1 (2.8)		

<sup>a</sup>6 missing cases (4 in London and 2 in Nottingham).

### **8.3 EXPLORATION OF DIFFERENCES BY ETHNICITY AND SUBSTANCE USE**

Tables 11 and 12 show the social and clinical characteristics of the final sample (N=325) by drug use and alcohol use. There were significantly more males than females with comorbid drug use disorders ( $\chi^2=33.412$ , d.f.=2,  $p=0.000$ ), and significantly more patients with comorbid drug use disorders in the younger 16-29 age group than the older age group ( $\chi^2=39.360$ , d.f.=2,  $p=0.000$ ). There were also significantly more Black Africans in the non-drug user group ( $\chi^2=13.122$ , d.f.=4,  $p=0.011$ ). Patients with drug use or comorbid drug use disorder were less likely to have a diagnosis of depression ( $\chi^2=13.815$ , d.f.=4,  $p=0.008$ ).

When we look at the characteristic of the sample by alcohol use we see that there was a higher proportion of patients with no alcohol use over their lifetime before in the London (81%) centre than in the Nottingham (19%) centre ( $\chi^2=11.048$ , d.f.=2,  $p=0.004$ ). There were also significantly more Black African than White or Black Caribbean patients with no alcohol use ( $\chi^2=25.330$ , d.f.=4,  $p=0.000$ ), which may have explained the higher proportion of no alcohol users in the London sample.

Patients with comorbid alcohol use disorders tended to be male (72%,  $\chi^2=16.277$ , d.f.=2,  $p=0.000$ ) and tended to have a diagnosis of Schizophrenia (85%,  $\chi^2=8.836$ , d.f.=4,  $p=0.065$ ) although this didn't quite reach statistical significance.

When we look at the characteristics of the sample by ethnic group we can see from Table 13 that apart from a higher percentage of no drug use in the Black African group and a higher percentage of alcohol use in the White group the only other significant differences were with the ethnic distribution by study centre. London had significantly more Black Caribbean (London,  $n=94$  vs. Nottingham,  $n=14$ ) and Black African



(London, n=46 vs. Nottingham, n=1) patients than Nottingham ( $\chi^2=121.253$ , d.f.=2, p=0.000).

**Table 11: Social and clinical characteristics by drug use**

	No drug use N (%)	Drug Use N (%)	Comorbid DUD N (%)	$\chi^2$	d.f.	P
<b>Study Centre<sup>a</sup></b>						
London	78 (60.0)	55 (64.7)	45 (69.2)	1.662	2	0.436
Nottingham	52 (40.0)	30 (35.3)	20 (30.8)			
<b>Social<sup>a</sup></b>						
<b>Gender<sup>a</sup></b>						
Male	47 (36.2)	51 (60.0)	51 (78.5)	33.412	2	0.000
Female	83 (63.8)	34 (40.0)	14 (21.5)			
<b>Age<sup>a</sup></b>						
16-29	43 (33.1)	54 (63.5)	50 (76.9)	39.360	2	0.000
30 yrs and over	87 (66.9)	31 (36.5)	15 (23.1)			
<b>Ethnicity<sup>a</sup></b>						
White	60 (46.2)	49 (57.6)	33 (50.8)	13.122	4	0.011
Black Caribbean	40 (30.8)	30 (35.3)	26 (40.0)			
Black African	30 (23.1)	6 (7.1)	6 (9.2)			
<b>Clinical<sup>b</sup></b>						
<b>Diagnosis<sup>b</sup></b>						
Schizophrenia	93 (71.5)	61 (71.8)	54 (84.4)	13.815	4	0.008
Mania	12 (9.2)	17 (20.0)	5 (7.8)			
Depression	25 (19.2)	7 (8.2)	5 (7.8)			

<sup>a</sup>45 missing cases.

<sup>b</sup>46 missing cases.

**Table 12: Social and clinical characteristics by alcohol use**

	No alcohol use N (%)	Alcohol Use N (%)	Comorbid AUD N (%)	$\chi^2$	d.f.	P
Study Centre <sup>a</sup>						
London	46 (80.7)	100 (56.5)	31 (66.0)	11.048	2	0.004
Nottingham	11 (19.3)	77 (43.5)	16 (34.0)			
Social <sup>a</sup>						
Gender <sup>a</sup>						
Male	19 (33.3)	98 (55.4)	34 (72.3)	16.277	2	0.000
Female	38 (66.7)	79 (44.6)	13 (27.7)			
Age <sup>a</sup>						
16-29	25 (43.9)	95 (53.7)	27 (57.4)	2.260	2	0.323
30 yrs and over	32 (56.1)	82 (46.3)	20 (42.6)			
Ethnicity <sup>a</sup>						
White	15 (26.3)	101 (57.1)	27 (57.4)	25.330	4	0.000
Black Caribbean	24 (42.1)	57 (32.2)	17 (36.2)			
Black African	18 (31.6)	19 (10.7)	3 (6.4)			
Clinical <sup>b</sup>						
Diagnosis <sup>b</sup>						
Schizophrenia	39 (68.4)	129 (73.3)	40 (85.1)	8.836	4	0.065
Mania	5 (8.8)	26 (14.8)	4 (8.5)			
Depression	13 (22.8)	21 (11.9)	3 (6.4)			

<sup>a</sup>44 missing cases.

<sup>b</sup>45 missing cases.

**Table 13: Social and clinical characteristics by ethnicity**

	White N (%)	Black Caribbean N (%)	Black African N (%)	$\chi^2$	d.f.	P
Study Centre						
London	52 (30.6)	94 (87.0)	46 (97.9)	121.253	2	0.000
Nottingham	118 (69.4)	14 (13.0)	1 (2.1)			
Social						
Gender						
Male	99 (58.2)	54 (50.0)	25 (53.2)	1.863	2	0.394
Female	71 (41.8)	54 (50.0)	22 (46.8)			
Age						
16-29	87 (51.2)	55 (50.9)	29 (61.7)	1.821	2	0.402
30 yrs and over	83 (48.8)	53 (49.1)	18 (38.3)			
Clinical <sup>a</sup>						
Diagnosis						
Schizophrenia	119 (70.4)	90 (83.3)	33 (70.2)	9.004	4	0.061
Mania	21 (12.4)	12 (11.1)	7 (14.9)			
Depression	29 (17.2)	6 (5.6)	7 (14.9)			
Substance Use						
Drug Use <sup>b</sup>						
No drug use	60 (42.3)	40 (41.7)	30 (71.4)	13.122	4	0.011
Drug use	49 (34.5)	30 (31.2)	6 (14.3)			
Comorbid DUD	33 (23.2)	26 (27.1)	6 (14.3)			
Alcohol Use <sup>c</sup>						
No alcohol use	15 (10.5)	24 (24.5)	18 (45.0)	25.330	4	0.000
Alcohol use	101 (70.6)	57 (58.2)	19 (47.5)			
Comorbid AUD	27 (18.9)	17 (17.3)	3 (7.5)			

<sup>a</sup>72 missing cases.

<sup>b</sup>45 missing cases.

<sup>c</sup>44 missing cases.

As we can see from exploration of the differences in the study sample there were significant differences in the age, gender, ethnicity and diagnosis of patients with comorbid DUD and significant differences in the gender, ethnicity and study centre of patients with comorbid AUD. There were also differences by ethnicity. The main differences were:

- There was significantly less drug and alcohol use as well as drug and alcohol use disorders in Black Africans.
- Patients with comorbidity were more likely to be male, young and have a diagnosis of schizophrenia.
- Patients with comorbid alcohol use disorders were more likely to be male, have a diagnosis of Schizophrenia and to have been recruited from the London study site.
- There were significantly less Black Caribbean and Black African patients in the Nottingham sample.

Although these findings point towards ethnic differences in the prevalence of drug and alcohol use as well as differences in social and clinical characteristics between those with and without substance use disorders, further exploration was needed to answer the two research questions. The subsequent sections looked at ethnicity as a risk factor for comorbid drug or alcohol use disorder and then comorbidity as a risk factor for psychotic relapse and hospital admission.

To recap, the study hypotheses were as follows:

- 1) The prevalence of comorbid substance use disorders in individuals with an 8-12 year history of psychosis will differ according to ethnic group.

More specifically, rates of comorbidity will be higher in Black Caribbean and lower in Black African patients than White patients.

- 2) In all ethnic groups comorbid substance use disorder will be associated with:
  - a) More frequent relapses
  - b) More compulsory admissions and independent of potential confounders, including age, gender, diagnosis and study centre.

To answer the first hypotheses the odds or the likelihood of having either substance use or a comorbid substance use disorder by ethnic group were calculated. To address both parts of the second hypotheses odds and rate (risk) ratios were calculated for the whole sample and then (where possible) for each ethnic group separately so that comparisons could be made. As highlighted in the chapter covering the analytical structure of the PhD study (Chapter 7), regression analyses allow for the effect of ethnicity and comorbidity to be uncovered as well as for interaction effects to be estimated, while adjusting for potential confounders. Unadjusted odds and rate ratios were calculated first and where possible analyses were stratified by study centre. Following that, adjusted odds and rate ratios were calculated using a priori confounder's age, gender and diagnosis as well as study centre.

#### **8.4 ETHNIC DIFFERENCES IN THE LIKELIHOOD OF HAVING SUBSTANCE USE DISORDERS**

As discussed in Chapter 7, multinomial regression analyses were used to test the first research hypotheses. The three-level comorbid drug use disorder variable used compared non-drug users (N=130) (patients who had never used drugs in their lifetime before their follow-up) with patients who had used drugs at least once in their lifetime before follow-up but didn't score for a drug use disorder (N=85), while simultaneously comparing non-drug users with patients who had a diagnosed drug use disorder (drug abuse or drug dependence) (N=65) in their lifetime before follow-up.

Using 'no drug use' as the reference group for all analyses, the odds ratios (OR) for having drug use over the follow-up period were compared by ethnic group. Table 14 shows that Black Caribbean patients had roughly equivalent odds of having drug use compared with White patients (OR 0.918, CI 0.501-1.682,  $p=0.783$ ), however Black Africans were 0.2 less likely than Whites to have drug use (OR 0.245, CI 0.094-0.636,

$p=0.004$ ). A similar pattern was observed for the ORs for having a comorbid drug use disorder (DUD). Black Caribbeans had similar odds of having a comorbid DUD (OR 1.182, CI 0.616-2.267,  $p=0.615$ ) while Black Africans were significantly less likely to have a comorbid DUD compared with Whites (OR 0.364, CI 0.137-0.963,  $p=0.042$ ).

A priori confounders were set for this study. As well as age, gender and diagnosis, study centre was set as a confounder. Although there were significant ethnic differences between the London and Nottingham sites (see Table 10) the number of patients in the Black African group was too small to report stratified analyses for drug or alcohol use. After adjusting for the a priori confounders, Black Caribbeans were half as likely to have used drugs compared with Whites (OR 0.501, CI 0.224-1.119,  $p=0.092$ ). As with the unadjusted odds, Black Africans were much less likely to have used drugs over the follow-up (OR 0.073, CI 0.022-0.241,  $p=0.000$ ).

Similar odds were observed when ethnic differences in likelihood of comorbid DUD were examined, with Black Africans being significantly less likely to have a comorbid DUD (BC vs. W: OR 0.689, CI 0.280-1.697,  $p=0.419$ ; BA vs. W: OR 0.090, CI 0.025-0.327,  $p=0.000$ ).

**Table 14: Ethnicity and prevalence of drug use and drug use disorders**

	No drug use <b>N (%)</b>	Drug use <b>N (%)</b>	<b>Unadjusted Odds Ratios</b>	<b>95% CI</b>	<b>p</b>	Comorbid DUD <b>N (%)</b>	<b>Unadjusted Odds Ratios</b>	<b>95% CI</b>	<b>p</b>
<b>Ethnicity</b>									
<b>White</b>	60 (46.2)	49 (57.6)	1.00	-	-	33 (50.8)	1.00	-	-
<b>Black Caribbean</b>	40 (30.8)	30 (35.3)	0.918	0.501-1.682	0.783	26 (40.0)	1.182	0.616-2.267	0.615
<b>Black African</b>	30 (23.1)	6 (7.1)	0.245	0.094-0.636	0.004	6 (9.2)	0.364	0.137-0.963	0.042

CI, confidence interval.



**Table 15: Ethnicity and prevalence of alcohol use and alcohol use disorders**

	No alcohol use <b>N (%)</b>	Alcohol use <b>N (%)</b>	<b>Unadjusted Odds Ratios</b>	<b>95% CI</b>	<b>p</b>	Comorbid AUD <b>N (%)</b>	<b>Unadjusted Odds Ratios</b>	<b>95% CI</b>	<b>p</b>
<b>Ethnicity</b>									
<b>White</b>	15 (26.3)	101 (57.1)	1.00	-	-	27 (57.4)	1.00	-	-
<b>Black Caribbean</b>	24 (42.1)	57 (32.2)	0.353	0.171-0.726	0.005	17 (36.2)	0.394	0.162-0.954	0.039
<b>Black African</b>	18 (31.6)	19 (10.7)	0.157	0.068-0.364	0.000	3 (6.4)	0.093	0.023-0.366	0.001

CI, confidence interval.

**Table 16: Ethnicity and prevalence of drug use and drug use disorders**

	No drug use <b>N (%)</b>	Drug use <b>N (%)</b>	<b>Adjusted Odds Ratios<sup>a</sup></b>	<b>95% CI</b>	<b>p</b>	Comorbid DUD <b>N (%)</b>	<b>Adjusted Odds Ratios<sup>a</sup></b>	<b>95% CI</b>	<b>p</b>
<b>Ethnicity</b>									
<b>White</b>	60 (46.2)	49 (57.6)	1.00	-	-	33 (50.8)	1.00	-	-
<b>Black Caribbean</b>	40 (30.8)	30 (35.3)	0.501	0.224-1.119	0.092	26 (40.0)	0.689	0.280-1.697	0.419
<b>Black African</b>	30 (23.1)	6 (7.1)	0.073	0.022-0.241	0.000	6 (9.2)	0.090	0.025-0.327	0.000

CI, confidence interval.

<sup>a</sup>Adjusted for age, gender, diagnosis and study centre.

**Table 17: Ethnicity and prevalence of alcohol use and alcohol use disorders**

	No alcohol use <b>N (%)</b>	Alcohol use <b>N (%)</b>	<b>Adjusted Odds Ratios</b>	<b>95% CI</b>	<b>p</b>	Comorbid AUD <b>N (%)</b>	<b>Adjusted Odds Ratios</b>	<b>95% CI</b>	<b>p</b>
<b>Ethnicity</b>									
<b>White</b>	15 (26.3)	101 (57.1)	1.00	-	-	27 (57.4)	1.00	-	-
<b>Black Caribbean</b>	24 (42.1)	57 (32.2)	0.376	0.149-0.949	0.038	17 (36.2)	0.290	0.095-0.885	0.030
<b>Black African</b>	18 (31.6)	19 (10.7)	0.174	0.059-0.511	0.001	3 (6.4)	0.066	0.013-0.322	0.001

CI, confidence interval.

<sup>a</sup>Adjusted for age, gender, diagnosis and study centre.

Next the likelihood of using alcohol and having an AUD was examined (see Table 15). Again a three-level variable was used. The variable compared patients who had never used alcohol in their lifetime before study follow-up (N=57) with patients who had used alcohol at least once in their lifetime but didn't score for an alcohol use disorder (N=177) as well as patients who had a diagnosed alcohol use disorder (alcohol abuse or alcohol dependence) (N=47) in their lifetime before follow-up.

Black Caribbeans with under 0.4 the odds of Whites were significantly less likely to have used alcohol or have had an alcohol use disorder (Alcohol use: OR 0.353, CI 0.171-0.726,  $p=0.005$ ; Comorbid AUD: OR 0.394, CI 0.162-0.954,  $p=0.039$ ). The same pattern was observed in Black Africans who had roughly 0.1 the odds of Whites (Alcohol use: OR 0.157, CI 0.068-0.364,  $p=0.000$ ; Comorbid AUD: OR 0.093, CI 0.023-0.366,  $p=0.001$ ). This preliminarily suggests that alcohol use and alcohol use disorders are much less likely in both Black ethnic groups.

After adjusting for a priori confounders the odds for both alcohol use and comorbid AUD in the Black Caribbean group remained equivalent (Alcohol use: OR 0.376, CI 0.149-0.949,  $p=0.038$ ; Comorbid AUD: OR 0.290, CI 0.095-0.885,  $p=0.030$ ) as did the odds for patients in the Black African group (Alcohol use: OR 0.174, CI 0.059-0.511,  $p=0.001$ ; Comorbid AUD: OR 0.066, CI 0.013-0.322,  $p=0.001$ ). Table 17 shows the likelihood for having alcohol use and alcohol use disorders in a patient's lifetime before with these adjustments.

Several conclusions can be drawn from the findings in the previous section and this section:

- Black Caribbean and White patients have equivalent lifetime before prevalence of drug use as well as equivalent lifetime before prevalence and likelihood of having comorbid drug use disorders. When key social and clinical variables are held constant Black

Caribbeans are half as less likely to have drug use and slightly less likely to have comorbidity.

- Black Africans on the other hand have significantly lower lifetime before prevalence and likelihood of having both lifetime before drug use and drug use disorders compared with Whites. When key social and clinical variables are held constant these findings hold.
- Black Caribbean and Black African patients have lower lifetime before prevalence and less likelihood of having lifetime before alcohol use and comorbid alcohol use disorders. When key social and clinical variables are held constant these patterns are even more apparent.

Given that the first hypotheses predicted higher prevalence of comorbid SUDs in the Black Caribbeans compared to Whites we cannot accept the primary experimental hypothesis for the study. Moreover a reverse pattern of use was found for alcohol use and alcohol use disorders in this ethnic group.

However, as we have seen, lower prevalence and likelihood of both drug and alcohol use as well as comorbid drug and alcohol use disorders in Black African patients was in line with the primary hypothesis.

## **8.5 RELATIONSHIP BETWEEN COMORBIDITY AND FREQUENCY OF RELAPSE**

The second hypothesis to be tested was whether, regardless of ethnic group, comorbidity was negatively associated with psychotic relapse. In other words, did having comorbid substance use disorder increase the likelihood of someone having more frequent episodes of psychotic illness? To measure frequency of relapse the variable 'number of psychotic episodes over follow-up' was used. The variable 'number of psychotic episodes' estimated the frequency of psychotic episodes patients had not including their baseline episode. Many of the patients only experienced their episode of inclusion into the AESOP baseline study.

Additionally, some of the patients were still in their episode of inclusion at follow-up or had episodes of illness with short periods of remission in between (a continuous illness), while others experienced, for example, several short episodes that were separated by longer periods of remission (an episodic illness).

The hypothesis was concerned with patients that had the latter presentation. It was hypothesised that patients with comorbid substance use disorders would have more relapses (in other words more psychotic episodes) and so, by association, would have an episodic or neither episodic nor continuous illness course. It was useful however to first see if there were any differences between those who had continuous, episodic or neither type of illness course and whether the likelihood of having a particular course type was related to comorbid substance use.

### **8.5.1 Relationship between comorbidity and illness course type**

Multinomial logistics regression was used to compare patients who had an episodic course type (i.e. their illness course included episodes that did not last longer than six months with at least six months of

remission between) (N=92) with those that had either a continuous course type (i.e. their illness course had no remission that lasted longer than six months) (N=67) and patients that had neither an episodic nor continuous course type (i.e. at least one episode and one remission lasted over six months) (N=131).

A three-level variable was used, with patients categorised as having an episodic illness course coded as '1', those with a continuous illness course coded as '2' and those with neither type of course type coded as '3'.

Table 18 shows how the analysis was split: firstly the risk of having an episodic or neither course was calculated for the whole sample (all three ethnic groups), then the risk for having an episodic or neither course type was calculated for each of the three ethnic groups separately. As with the analyses above two three-level variables for comorbid substance use were used (one for drugs and one for alcohol) to predict course type. The unadjusted odds for the whole sample and for each ethnic group for having an episodic course type compared to a continuous course type were mixed in the drug using group.

In the whole sample drug users had similar odds to non-drug users for having an episodic course type while patients with comorbid DUD were slightly less likely (OR 0.598, CI 0.247-1.449,  $p=0.255$ ). The opposite pattern was observed for the likelihood of having a neither episodic nor continuous course type, with drug users being less likely and patients with comorbid DUD having an equivalent odds to non-drug users (Drug use: OR 0.459, CI 0.222-0.948,  $p=0.035$ ; Comorbid DUD: OR 0.904, CI 0.418-1.955,  $p=0.797$ ).

When the three ethnic groups were looked at separately very different patterns were observed. White patients with drug use were 0.3 less likely to have an episodic course type compared to non-drug users while Black Caribbeans with drug use were over twice as likely to have an episodic course type compared to non-drug users (W: OR 0.326, CI

0.097-1.096,  $p=0.070$ ; BC: OR 2.333, CI 0.638-8.538,  $p=0.201$ ). Black African drug users had equivalent odds to non-drug users for having an episodic over a continuous illness course.

When comorbidity was examined, White patients with comorbid DUD were also significantly less likely than non-drug users to have an episodic course type, whereas Black Caribbean patients with comorbidity were 1.3 more likely to have an episodic course type (W: OR 0.290, CI 0.069-1.216,  $p=0.090$ ; BC: OR 1.333, CI 0.281-6.325,  $p=0.717$ ). Black Africans with comorbidity had 0.6 the odds of having an episodic course type compared with Black African non-drug users (OR 0.600, CI 0.066-5.447,  $p=0.650$ ). However the confidence intervals for odds of the Black African and Black Caribbeans with comorbid DUD were very large and numbers for Black Africans in both the episodic and continuous groups were very small.

It should be noted that numbers in the White and Black African groups (specifically for patients with a continuous illness course) were very small. In the drug use adjusted analyses numbers in the depression group for diagnoses were very small for White patients and in the alcohol analyses several expected counts for White and Black African patients were fewer than 5<sup>2</sup> making it impossible to calculate likelihoods for these two groups. Subsequently a summary for the whole sample and for Black Caribbeans is given for adjusted analyses for drug use and both unadjusted and adjusted analyses for alcohol use.

When the odds for having an episodic course type (see Table 20) for the whole sample were adjusted for a priori confounders, patients with drug use had equivalent odds to those with no drug use for having

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<sup>2</sup> There are assumptions and restrictions in the statistical analysis of contingency tables which logistic regression analysis is based on. "No more than 20% of the expected counts are less than 5 and all individual expected counts are 1 or greater" (Yates, Moore & McCabe, 1999, p. 734). In addition Yates, Moore and McCabe suggest that it is acceptable to have some expected counts less than 5, provided none are less than 1, and at least 80% of the expected counts are equal to or greater than 5.



an episodic vs. a continuous illness course (OR 0.936, CI 0.390-2.245,  $p=0.881$ ).

Patients with a comorbid DUD disorder had slightly higher odds of having an episodic course type although these findings had large confidence intervals and did not reach significance (OR 1.226, CI 0.429-3.506,  $p=0.704$ ).

**Table 18: Relationship between course type and drug use**

Type of illness course	Continuous N (%)	Episodic N (%)	Unadjusted Odds Ratios	95% CI	P	Neither N (%)	Unadjusted Odds Ratios	95% CI	p
<b>Whole sample<sup>a</sup></b>									
No drug use	25 (39.1)	39 (46.4)	1.000			59 (50.4)	1.000		
Drug use	24 (37.5)	31 (36.9)	0.828	0.398-1.722	0.613	26 (22.2)	0.459	0.222-0.948	0.035
Comorbid DUD	15 (23.4)	14 (16.7)	0.598	0.247-1.449	0.255	32 (27.4)	0.904	0.418-1.955	0.797
<b>White British</b>									
No drug use	5 (21.7)	23 (46.9)	1.000			30 (49.2)	1.000		
Drug use	12 (52.2)	18 (36.7)	0.326	0.097-1.096	0.070	15 (24.6)	0.208	0.062-0.701	0.011
Comorbid DUD	6 (26.1)	8 (16.3)	0.290	0.069-1.216	0.090	16 (26.2)	0.444	0.117-1.685	0.233
<b>Black Caribbean</b>									
No drug use	14 (45.2)	6 (30.0)	1.000			15 (38.5)	1.000		
Drug use	10 (32.3)	10 (50.0)	2.333	0.638-8.538	0.201	10 (25.6)	0.933	0.299-2.917	0.906
Comorbid DUD	7 (22.6)	4 (20.0)	1.333	0.281-6.325	0.717	14 (35.9)	1.867	0.583-5.975	0.293
<b>Black African</b>									
No drug use	6 (60.0)	10 (66.7)	1.000			14 (82.4)	1.000		
Drug use	2 (20.0)	3 (20.0)	0.900	0.115-7.031	0.920	1 (5.9)	0.214	0.016-2.839	0.243
Comorbid DUD	2 (20.0)	2 (13.3)	0.600	0.066-5.447	0.650	2 (11.8)	0.429	0.048-3.794	0.446

CI, confidence interval

<sup>a</sup> By study centre:

London

Episodic

Drug use *versus* No drug use

Unadjusted OR 1.599 (0.650-3.931)

Comorbid DUD *versus* No drug use

Unadjusted OR 0.926 (0.316-2.715)

Neither

Drug use *versus* No drug use

Unadjusted OR 0.565 (0.236-1.349)

Comorbid DUD *versus* No drug use

Unadjusted OR 1.100 (0.453-2.672)

Nottingham

Episodic

Drug use *versus* No drug use

Unadjusted OR 0.234\* (0.055-0.999)

Comorbid DUD *versus* No drug use

Unadjusted OR 0.303 (0.051-1.805)

Neither

Drug use *versus* No drug use

Unadjusted OR 0.238\* (0.057-0.998)

Comorbid DUD *versus* No drug use

Unadjusted OR 0.556 (0.105-2.948)

\* p<0.05

**Table 19: Relationship between course type and alcohol use**

Type of illness course	Continuous N (%)	Episodic N (%)	Unadjusted Odds Ratios	95% CI	P	Neither N (%)	Unadjusted Odds Ratios	95% CI	p
<b>Whole sample</b>									
No alcohol use	9 (14.3)	13 (14.9)	1.000			31 (26.1)	1.000		
Alcohol use	39 (61.9)	64 (73.6)	1.136	0.444-2.904	0.790	69 (58.0)	0.514	0.222-1.189	0.120
Comorbid AUD	15 (23.8)	10 (11.5)	0.462	0.144-1.483	0.194	19 (16.0)	0.368	0.135-1.004	0.051
<b>White British</b>									
No alcohol use	0 (0.0)	5 (9.4)	-			10 (16.4)	-		
Alcohol use	14 (63.6)	41 (77.4)	-	-	-	42 (68.9)	-	-	-
Comorbid AUD	8 (36.4)	7 (13.2)	-	-	-	9 (14.8)	-	-	-
<b>Black Caribbean</b>									
No alcohol use	4 (12.5)	3 (15.0)	1.000			13 (31.7)	1.000		
Alcohol use	21 (65.6)	15 (75.0)	0.952	0.185-4.895	0.953	20 (48.8)	0.293	0.082-1.051	0.060
Comorbid AUD	7 (21.9)	2 (10.0)	0.381	0.043-3.338	0.383	8 (19.5)	0.352	0.078-1.594	0.175
<b>Black African</b>									
No alcohol use	6 (60.0)	10 (66.7)	-			14 (82.4)	-		
Alcohol use	2 (20.0)	3 (20.0)	-	-	-	1 (5.9)	-	-	-
Comorbid AUD	2 (20.0)	2 (13.3)	-	-	-	2 (11.8)	-	-	-

CI, confidence interval.

**Table 20: Relationship between course type and drug use**

Type of illness course	Continuous N (%)	Episodic N (%)	Adjusted Odds Ratios	95% CI	P	Neither N (%)	Adjusted Odds Ratios	95% CI	p
<b>Whole sample</b>									
No drug use	25 (39.1)	39 (46.4)	1.000			59 (50.4)	1.000		
Drug use	24 (37.5)	31 (36.9)	0.936	0.390-2.245	0.881	26 (22.2)	0.553	0.252-1.211	0.138
Comorbid DUD	15 (23.4)	14 (16.7)	1.226	0.429-3.506	0.704	32 (27.4)	1.123	0.471-2.677	0.793
<b>White British</b>									
No drug use	5 (21.7)	23 (46.9)	-	-	-	30 (49.2)	-	-	-
Drug use	12 (52.2)	18 (36.7)	-	-	-	15 (24.6)	-	-	-
Comorbid DUD	6 (26.1)	8 (16.3)	-	-	-	16 (26.2)	-	-	-
<b>Black Caribbean</b>									
No drug use	14 (45.2)	6 (30.0)	1.000			15 (38.5)	1.000		
Drug use	10 (32.3)	10 (50.0)	2.443	0.584-10.226	0.221	10 (25.6)	1.415	0.413-4.845	0.580
Comorbid DUD	7 (22.6)	4 (20.0)	1.737	0.309-9.759	0.531	14 (35.9)	1.937	0.475-7.887	0.356
<b>Black African</b>									
No drug use	6 (60.0)	10 (66.7)	-	-	-	14 (82.4)	-	-	-
Drug use	2 (20.0)	3 (20.0)	-	-	-	1 (5.9)	-	-	-
Comorbid DUD	2 (20.0)	2 (13.3)	-	-	-	2 (11.8)	-	-	-

CI, confidence interval.

**Table 21: Relationship between course type and alcohol use**

Type of illness course	Continuous N (%)	Episodic N (%)	Adjusted Odds Ratios	95% CI	P	Neither N (%)	Adjusted Odds Ratios	95% CI	p
<b>Whole sample</b>									
No alcohol use	9 (14.3)	13 (14.9)	1.000			31 (26.1)	1.000		
Alcohol use	39 (61.9)	64 (73.6)	1.227	0.432-3.483	0.701	69 (58.0)	0.502	0.206-1.221	0.129
Comorbid AUD	15 (23.8)	10 (11.5)	0.758	0.207-2.772	0.676	19 (16.0)	0.407	0.141-1.178	0.097
<b>White British</b>									
No alcohol use	0 (0.0)	5 (9.4)	-			10 (16.4)	-		
Alcohol use	14 (63.6)	41 (77.4)	-	-	-	42 (68.9)	-	-	-
Comorbid AUD	8 (36.4)	7 (13.2)	-	-	-	9 (14.8)	-	-	-
<b>Black Caribbean</b>									
No alcohol use	4 (12.5)	3 (15.0)	1.000			13 (31.7)	1.000		
Alcohol use	21 (65.6)	15 (75.0)	1.077	0.267-4.337	0.917	20 (48.8)	0.501	0.164-1.533	0.226
Comorbid AUD	7 (21.9)	2 (10.0)	0.371	0.045-3.049	0.356	8 (19.5)	0.595	0.147-2.409	0.467
<b>Black African</b>									
No alcohol use	6 (60.0)	10 (66.7)	-			14 (82.4)	-		
Alcohol use	2 (20.0)	3 (20.0)	-	-	-	1 (5.9)	-	-	-
Comorbid AUD	2 (20.0)	2 (13.3)	-	-	-	2 (11.8)	-	-	-

CI, confidence interval.

When Black Caribbeans were examined separately drug users and patients with comorbidity had nearly double the likelihood of having an episodic course type (Drug use: OR 2.443, CI 0.584-10.226,  $p=0.221$ ; Comorbid DUD: OR 1.737, CI 0.309-9.759,  $p=0.531$ ), although, as with the unadjusted odds, these findings should be treated with caution as the confidence intervals for both groups were very wide.

Next the relationship between course type and alcohol use was analysed (see Table 19). In the whole sample alcohol users had an only-slightly-elevated likelihood of having an episodic course type over a continuous one compared with non-alcohol users (OR 1.136, CI 0.444-2.904,  $p=0.790$ ) while those with comorbidity had considerably less odds compared with non-alcohol users of having that type of illness course (OR 0.462, CI 0.144-1.483,  $p=0.194$ ). This pattern was almost identical when Black Caribbeans were examined separately.

All patients with alcohol use had half the odds of having a neither illness course compared with patients that hadn't used alcohol and patients with comorbid AUD were 0.3 less likely to have a neither episodic or continuous course type (Alcohol use: OR 0.514, CI 0.222-1.189,  $p=0.120$ ; Comorbid AUD: OR 0.368, CI 0.135-1.004,  $p=0.051$ ).

When Black Caribbeans were looked at separately a similar pattern for patients with comorbidity was found, However, patients with alcohol use had an even lower likelihood than the whole sample of having a neither illness course compared with patients with no alcohol use (OR 0.293, CI 0.082-1.051,  $p=0.060$ ).

When odds ratios for alcohol use were adjusted (Table 21) for then those patients with alcohol use retained their slightly higher odds for having an episodic course type (OR 1.227, CI 0.432-3.483,  $p=0.701$ ) while those with comorbid AUD were 0.7 less likely to have an episodic course type (OR 0.758, CI 0.207-2.772,  $p=0.676$ ).

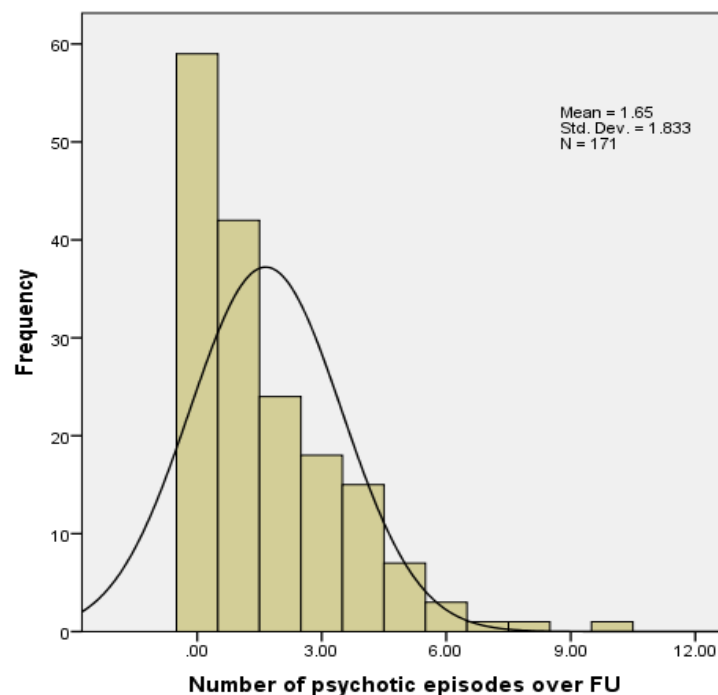
The adjusted odds of patients with alcohol use and comorbid AUD for having a neither episodic nor continuous illness course were similar to the unadjusted odds, with patients in both groups having approximately half the likelihood of those with no alcohol use (Alcohol use: OR 0.502, CI 0.206-1.221,  $p=0.129$ ; Comorbid AUD: OR 0.407, CI 0.141-1.178,  $p=0.097$ ). A similar pattern was observed in the Black Caribbean only sample.

### **8.5.2 Relationship between comorbidity and psychotic episodes**

For patients that had an episodic or neither episodic nor continuous illness course type rates of psychotic relapse were calculated. As we can see from Figure 14 the frequency of psychotic episodes for the whole sample was over-dispersed with patients that had no additional episode of illness, meaning that non-parametric tests for samples without normal distribution were used to explore differences between ethnic groups and risk factors for having high frequency of relapses.

The number of relapses patients had ranged from 0-12, with the majority having fewer than 3 episodes of illness. A Kruskal-Wallis ANOVA was conducted to compare the average number of psychotic episodes in each ethnic group. As we can see from Table 22 no significant differences in the frequency of psychotic relapse was found between the three ethnic groups ( $\chi^2 = 2.945$ , d.f. =2,  $p=0.229$ ).

**Figure 14: Number of psychotic episodes over follow-up**



As we can see from Figure 14 the data for patients with an episodic or neither course type had an over dispersion of zeros and was not normally distributed. This type of data would normally require a negative binomial regression (Cameron, 2009)<sup>3</sup>. In addition to over dispersion of zeros, inequality between the conditional means and conditional variances are another reason for using negative binomial regression.

When conditional means and variances were explored (see appendix 3) the differences were found to be minimal. Added to which, because the sample size was slightly smaller than it was in the other regression analyses<sup>4</sup> (due to the exclusion of patients with a continuous course type) risk for psychotic relapse was calculated using poisson regression.

<sup>3</sup> Zero inflated regression analyses are also advised for when dealing with over-dispersion of zeros; however this is reserved for data which generate more than one type of 'zero'.

<sup>4</sup> The UCLA Statistical Consulting Group does not recommend using Negative Binomial Regression analyses for small sample sizes.



Despite finding no difference in the average number of relapses between the three ethnic groups, there were several differences in the rates of psychotic relapse by ethnic group. When the sample was looked at as a whole the risk factor for having more psychotic relapses were equivalent in patients with drug use and comorbid DUD compared to patients that didn't have drug use. However, when each ethnic group was looked at separately different patterns of risk emerged despite numbers in the Black African group being too small to explore.

Table 23 shows rates of relapse for drug users compared to non-users where slightly higher in the White group and slightly lower in the Black Caribbean group although these findings didn't reach statistical significance. Moreover, White patients had much lower rates of relapses if they had a comorbid DUD (RR 0.389, CI 0.169-0.897,  $p=0.027$ ), whereas Black Caribbeans with comorbid DUD had nearly twice the rate of relapse compared to those with no drug use (RR 1.901, CI 1.052-3.434,  $p=0.033$ ).

After adjustment (Table 23), these patterns were retained with only a slight reduction in rate ratios for those in the Black Caribbean group (White: RR 0.367, CI 0.153-0.879,  $p=0.024$ ; Black Caribbean: RR 1.654, CI 0.610-4.488,  $p=0.323$ ). When rates of relapses were looked at for alcohol use a completely different pattern was observed.

In the whole sample patients with alcohol use and comorbid alcohol use (Table 24) had slightly lower rates of relapse compared to non-alcohol users (Alcohol use: RR 0.656, CI 0.437-0.986,  $p=0.043$ ; Comorbid AUD: RR 0.754, CI 0.422-1.345,  $p=0.339$ ). White patients had slightly higher rates of relapse if they had comorbid AUD. However, both Black Caribbean and Black African patients had half the rate of risk for psychotic episodes if they had either alcohol use (BC: RR 0.545, CI 0.292-1.020,  $p=0.058$ ; BA: RR 0.655, CI 0.334-1.283,  $p=0.217$ ) or comorbid AUD (in just the Black Caribbean group) (RR 0.593 CI 0.228-1.542,  $p=0.284$ ).

When rate ratios were adjusted for a priori confounders these patterns were roughly retained (Table 24). However, rates in the White group for both drug use and comorbid DUD were slightly more elevated and rates in Black Caribbean drug users and Black Africans with comorbidity were even lower, while also reaching statistical significance (BC drug use: RR 0.361, CI 0.196-0.668,  $p=0.001$ ; BA Comorbid DUD: RR 0.162, CI 0.057-0.463,  $p=0.001$ ).

**Table 22: Differences in number of psychotic episodes in patients with an episodic or neither illness course type by ethnicity**

<b>No. of psychotic episodes over FU</b>	<b>White n (%) / N</b>	<b>Black Caribbean n (%) / N</b>	<b>Black African n (%) / N</b>	$\chi^2$	<b>d.f.</b>	<b>p</b>
<b>Descriptives</b>	88 (52)/170	56 (52)/108	27 (57)/47			
Median	1.000	1.000	2.000			
SD	1.64447	2.12766	1.70051	2.945	2	0.229
Range	0-7	0-10	0-8			

**Table 23: Relationship between no. of psychotic episodes and comorbid DUD in patients with a non-continuous illness course type**

Psychotic episodes in patients with episodic or neither course type	Unadjusted Rate Ratio	95% CI	P	Adjusted Rate Ratio <sup>a</sup>	95% CI	p
<b>Whole sample<sup>b</sup> (n=202)</b>						
No drug use	1.000			1.000		
Drug use	1.003	0.689-1.459	0.989	0.931	0.651-1.332	0.696
Comorbid DUD	1.075	0.658-1.755	0.773	0.932	0.550-1.579	0.793
<b>White British (n=111, 54.1%)</b>						
No drug use	1.000			1.000		
Drug use	1.210	0.726-2.017	0.465	1.212	0.704-2.086	0.488
Comorbid DUD	0.389	0.169-0.897	0.027	0.367	0.153-0.879	0.024
<b>Black Caribbean (n=62, 30.2%)</b>						
No drug use	1.000			1.000		
Drug use	0.631	0.324-1.229	0.175	0.649	0.296-1.421	0.280
Comorbid DUD	1.901	1.052-3.434	0.033	1.654	0.610-4.488	0.323
<b>Black African (n=32, 15.6%)</b>						
No drug use	-	-	-	-	-	-
Drug use	-	-	-	-	-	-
Comorbid DUD	-	-	-	-	-	-

CI, confidence interval.

<sup>a</sup>Adjusted for age, gender, diagnosis and study centre.

<sup>b</sup>By study centre:

London

Drug use *versus* No drug use

Unadjusted RR 0.939 (0.599-1.473)

Comorbid DUD *versus* No drug use

Unadjusted RR 0.974 (0.521-1.822)

Nottingham

Drug use *versus* No drug use

Unadjusted RR 1.134 (0.604-2.128)

Comorbid DUD *versus* No drug use

Unadjusted RR 1.296 (0.623-2.696)

\* p<0.05

**Table 24: Relationship between no. of psychotic episodes and comorbid AUD in patients with a non-continuous illness course type**

Psychotic episodes in patients with episodic or neither course type	Unadjusted Rate Ratio	95% CI	P	Adjusted Rate Ratio <sup>a</sup>	95% CI	p
<b>Whole sample<sup>b</sup> (n=209)</b>						
No alcohol use	1.000			1.000		
Alcohol use	0.656	0.437-0.986	0.043	0.617	0.396-0.964	0.034
Comorbid AUD	0.754	0.422-1.345	0.339	0.672	0.347-1.302	0.239
<b>White British (n=115, 55.0%)</b>						
No alcohol use	1.000			1.000		
Alcohol use	1.142	0.559-2.333	0.715	1.417	0.648-3.096	0.382
Comorbid AUD	1.528	0.656-3.559	0.326	1.855	0.734-4.690	0.192
<b>Black Caribbean (n=63, 30.1%)</b>						
No alcohol use	1.000			1.000		
Alcohol use	0.545	0.292-1.020	0.058	0.361	0.196-0.668	0.001
Comorbid AUD	0.593	0.228-1.542	0.284	0.534	0.222-1.285	0.161
<b>Black African (n=31, 14.8%)</b>						
No alcohol use	1.000			1.000		
Alcohol use	0.655	0.334-1.283	0.217	0.487	0.264-0.901	0.022
Comorbid AUD	0.208	0.047-0.919	0.038	0.162	0.057-0.463	0.001

CI, confidence interval.

<sup>a</sup>Adjusted for age, gender, diagnosis and study centre.

<sup>b</sup>By study centre:

London	Alcohol use <i>versus</i> No alcohol use	Unadjusted RR 0.513* (0.322-0.815)
	Comorbid AUD <i>versus</i> No alcohol use	Unadjusted RR 0.612 (0.297-1.260)
Nottingham	Alcohol use <i>versus</i> No alcohol use	Unadjusted RR 1.268 (0.604-2.665)
	Comorbid AUD <i>versus</i> No alcohol use	Unadjusted RR 1.600 (0.712-3.597)

\* p<0.05

When we take the findings from both sections 8.4.1 and 8.4.2 together and look at them in relation to the second hypothesis (whether, regardless of ethnic group, comorbidity was negatively associated with psychotic relapse), we find that comorbidity is associated negatively with psychotic relapse but that the relationship differs in strength by ethnic group. Contrary to what was expected, these findings show that:

- The likelihoods of having either an episodic course or a neither episodic nor continuous course type are lower for the whole sample, White and Black African patients with drug use and comorbid drug use disorders, yet higher in Black Caribbean patients with drug use and comorbid drug use disorders.
- Although adjusted findings for White and Black African patients were not possible we can see that findings for the whole sample are drastically changed (increased likelihood of an either or neither course type in the comorbid group) when other sociodemographic and clinical variables are held constant. Black Caribbeans retain their increased likelihood.
- When the full samples of patients and Black Caribbean patients only were looked at those with a comorbid alcohol use disorder are around half as likely to have an episodic or neither course and these likelihoods are roughly retained when a priori confounders are adjusted for.
- For patients that have a non-continuous type illness course, the average number of psychotic episodes was similar in all three ethnic groups. However, Black Caribbeans with comorbid drug use disorders have higher risk of more frequent relapses, while Whites with comorbid drug use disorders have lower risk.
- The opposite is observed for Black Caribbean and White patients with alcohol use disorders.
- Black Africans with comorbid alcohol use disorder have an even lower risk for more frequent psychotic relapses.

## **8.6 RELATIONSHIP BETWEEN COMORBIDITY AND HOSPITALISATION**

The second hypothesis for the quantitative investigation was concerned with the relationship between comorbidity and hospitalisation. It was hypothesised that comorbidity, irrespective of ethnic group, would be associated with more compulsory admissions. To give this investigation context, differences in the number of hospital admissions was examined first.

### **8.6.1 Relationship between comorbidity and frequency of hospital admissions**

The median number of hospital admissions over the follow-up period was 2 (Range 0–14) for White British patients, 3 (Range 0–20) for Black Caribbean patients and 2 (Range 0–15) for Black African patients (see Figure 15 and Table 25). As with the analyses above, two three-level variables (one for drugs and one for alcohol) were used as the predictor for frequency of hospital admission, using 'no use' as the reference group for all analyses.

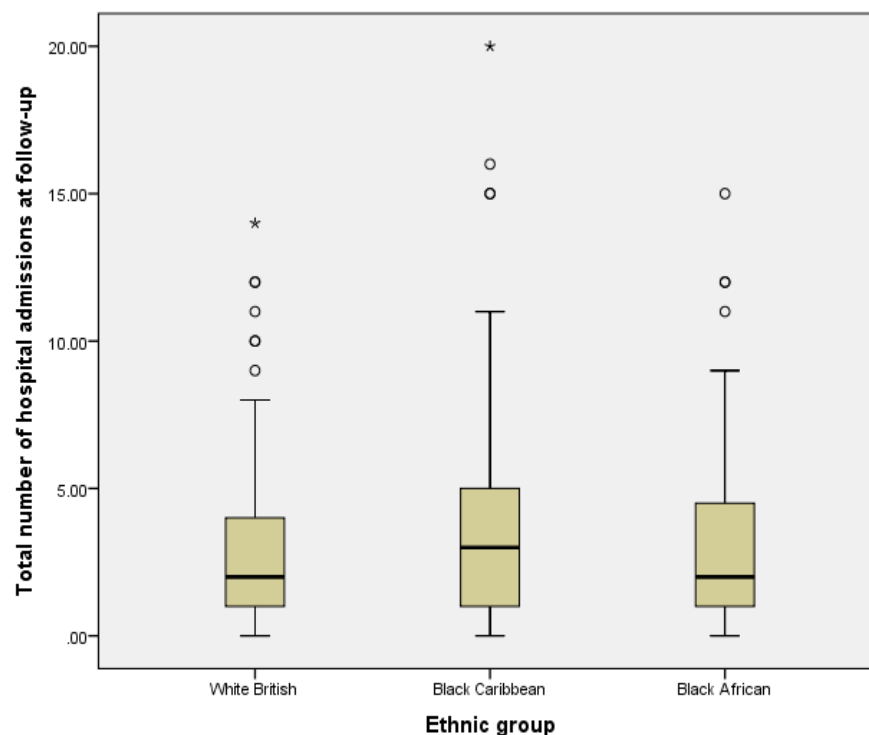
Exploratory analyses were conducted to make sure the data met the criteria for poisson regression analyses. The data had an over-dispersion of zeros and was not normally. When the conditional means and conditional variances were examined (see Appendix 3) it was found that they differed considerably from each other. Given that there was a sample size of nearly 300 cases, negative binomial regression analyses was used to estimate rate ratios for frequency of hospital admissions in people with drug and alcohol use. This regression analyses uses the same statistical structure as poisson regression, but allows for over-dispersion of zeros in the data.

Table 26 shows the rate ratios (RR) for having a high frequency of hospital admissions over the follow-up period if you have a comorbid drug use disorder. When the sample was looked at as a whole patients with drug use had roughly equivalent rates of hospital admissions to those who hadn't used drugs in their lifetime before, although the rates were slightly lower after adjustment for confounders (RR 0.896, CI 0.680-1.181,  $p=0.437$ ). Patients with a comorbid drug use disorder, at just over 1.3 times the rate of non-drug users, were significantly more likely to have more hospital admissions (RR 1.365, CI 1.038-1.795,  $p=0.026$ ).

A similar pattern was uncovered after adjustment of confounders (RR 1.288, CI 0.952-1.742,  $p=0.100$ ). Stratified unadjusted analyses were performed for rates of hospital admissions by study centre. Rates for hospital admissions for the London and Nottingham centres were examined separately. Patients in the London sample with comorbidity had similar rates to non-drug users however in the Nottingham sample patients with comorbidity had nearly twice the risk for high frequency of admissions (London: RR 1.164, CI 0.834-1.624,  $p=0.371$ ; Nottingham: RR 1.821, CI 1.156-2.871,  $p=0.010$ ).



**Figure 15: Total number of hospital admissions at follow up by ethnic group**



Next, the likelihood for having more hospital admissions over the follow-up was estimated for each ethnic group (see Table 26). In the White British group, those with drug use and those with a comorbid DUD (when compared to those with no use) were significantly more likely to have more hospital admissions (Drug use: RR 1.518, CI 1.074-2.145,  $p=0.018$ ; Comorbid DUD: RR 1.387 CI 0.939-2.051,  $p=0.101$ ).

When rate ratios were adjusted for only the patients with drug use retained higher rates of hospital admissions (Drug: RR 1.268, CI 0.862-1.864,  $p=0.228$ ; Comorbid DUD: RR 1.079, CI 0.692-1.685,  $p=0.736$ ). Black Caribbeans with drug use had 0.6 the risk for frequent hospital admissions while patients with comorbidity had around 1.6 the risk compared with non-drug users. These rate ratios held when a priori confounders were controlled for (Drug use: RR 0.670, CI 0.415-1.081,  $p=0.101$ ; Comorbid DUD: RR 1.636, CI 0.983-2.722,  $p=0.058$ ).

Black Africans also had a different pattern of rate ratios from the whole sample. The unadjusted rates for both drug users and those with

comorbidity were lower than for patients that didn't use drugs (Drug use: RR 0.680, CI 0.290-1.590,  $p=0.373$ ; Comorbid DUD: RR 0.566, CI 0.236-1.358,  $p=0.203$ ). When other confounders were adjusted for these rate ratios increased making them similar to patients who didn't use drugs (Drug use: RR 0.790, CI 0.326-1.916,  $p=0.602$ ; Comorbid DUD: RR 0.755, CI 0.314-1.818,  $p=0.531$ ).

The rates for high frequency of hospital admission when a patient had an alcohol use disorder were also mixed (see Table 27). When analyses focused on the whole sample both patients with alcohol use and alcohol use disorders had a lower risk for having lots of hospital admissions than patients who had never used alcohol in their lifetime before follow-up and after adjustment for confounders these rates were maintained (Alcohol use: RR 0.699, CI 0.524-0.933,  $p=0.015$ ; Comorbid AUD: RR 0.757, CI 0.520-1.100,  $p=0.144$ ).

Stratified analyses were again performed for unadjusted rate ratios. Patients with comorbid AUD (as with alcohol use) from the London study centre had lower rates of hospital admissions compared to non-drug users, while patients recruited from the Nottingham centre had higher rates of risk (London Comorbid AUD: RR 0.740 CI 0.491-1.116,  $p=0.151$ ; Nottingham Comorbid AUD: RR 1.432, CI 0.661-3.103,  $p=0.363$ ).

Rates varied by ethnic group. White patients who used alcohol or who had an alcohol use disorder had significantly higher rates (compared to patients who had never used alcohol) for having had frequent admissions over the follow-up (Alcohol use: RR 1.614, CI 0.928-2.807,  $p=0.090$ ; Comorbid AUD: RR 1.938, CI 1.037-3.625,  $p=0.038$ ). Although rates remained higher for these two groups after adjustment the difference in rate ratios compared to non-alcohol users did not reach significance (Alcohol use: RR 1.498, CI 0.850-2.640,  $p=0.163$ ; Comorbid AUD: RR 1.623, CI 0.839-3.140,  $p=0.150$ ).

Black Caribbean and Black African alcohol users both had around 0.6 the risk of non-users for having more hospital admissions which remained the same after adjustment. Black Caribbeans with comorbid alcohol use had around 0.7 the risk for high frequency of hospital admissions compared to non-users after adjustment (RR 0.680, CI 0.391-1.183,  $p=0.172$ ), however, with a rate ratio of just 0.1, an even lower rate was observed in Black Africans with comorbidity after adjustment (RR 0.147, CI 0.029-0.748,  $p=0.021$ ).

**Table 25: Difference in number of hospital admissions by ethnicity**

<b>No. of hospital admissions over FU</b>	<b>White N</b>	<b>Black Caribbean N</b>	<b>Black African N</b>	$\chi^2$	<b>d.f.</b>	<b>p</b>
<b>Descriptives<sup>a</sup></b>	170	108	47			
Median	2.0000	3.0000	2.0000			
SD	2.71877	3.79121	3.79383	6.024	2	0.049
Range	0-14	0-20	0-15			

<sup>a</sup>39 missing cases.

**Table 26: Relationship between hospital admission, drug use and comorbid drug use disorder**

Hospital admissions over the FU period	Unadjusted Rate Ratios	95% CI	p	Adjusted Rate Ratios <sup>a</sup>	95% CI	p
<b>Whole Sample<sup>b</sup></b>						
No drug use	1.000			1.000		
Drug use	0.943	0.726-1.227	0.664	0.896	0.680-1.181	0.437
Comorbid DUD	1.365	1.038-1.795	0.026	1.288	0.952-1.742	0.100
<b>White British</b>						
No drug use	1.000			1.000		
Drug use	1.518	1.074-2.145	0.018	1.268	0.862-1.864	0.228
Comorbid DUD	1.387	0.939-2.051	0.101	1.079	0.692-1.685	0.736
<b>Black Caribbean</b>						
No drug use	1.000			1.000		
Drug use	0.669	0.437-1.023	0.064	0.670	0.415-1.081	0.101
Comorbid DUD	1.667	1.115-2.494	0.013	1.636	0.983-2.722	0.058
<b>Black African</b>						
No drug use	1.000			1.000		
Drug use	0.680	0.290-1.590	0.373	0.790	0.326-1.916	0.602
Comorbid DUD	0.566	0.236-1.358	0.203	0.755	0.314-1.818	0.531

CI, confidence interval.

<sup>a</sup>Adjusted for age, gender, diagnosis and study centre.

<sup>b</sup>By study centre:

London	Drug use <i>versus</i> No drug use	Unadjusted RR 0.842 (0.610-1.163)
	Comorbid DUD <i>versus</i> No drug use	Unadjusted RR 1.164 (0.834-1.624)
Nottingham	Drug use <i>versus</i> No drug use	Unadjusted RR 1.138 (0.740-1.751)
	Comorbid DUD <i>versus</i> No drug use	Unadjusted RR 1.821* (1.156-2.871)

\* p<0.05

**Table 27: Relationship between hospital admission, alcohol use and comorbid alcohol use disorder**

Hospital admissions over the FU period	Unadjusted Rate Ratios	95% CI	p	Adjusted Rate Ratios <sup>a</sup>	95% CI	p
<b>Whole Sample<sup>bc</sup></b>						
No alcohol use	1.000	0.507-0.880	0.004	1.000	0.524-0.933	0.015
Alcohol use	0.668	0.534-1.097	0.146	0.699	0.520-1.100	0.144
Comorbid AUD	0.765			0.757		
<b>White British</b>						
No alcohol use	1.000	0.928-2.807	0.090	1.000	0.850-2.640	0.163
Alcohol use	1.614	1.037-3.625	0.038	1.498	0.839-3.140	0.150
Comorbid AUD	1.938			1.623		
<b>Black Caribbean</b>						
No alcohol use	1.000	0.385-0.906	0.016	1.000	0.310-0.768	0.002
Alcohol use	0.590	0.419-1.269	0.264	0.488	0.391-1.183	0.172
Comorbid AUD	0.729			0.680		
<b>Black African</b>						
No alcohol use	1.000	0.337-1.039	0.068	1.000	0.367-1.061	0.082
Alcohol use	0.592	0.024-0.633	0.012	0.624	0.029-0.748	0.021
Comorbid AUD	0.122			0.147		

CI, confidence interval

<sup>a</sup>Adjusted for age, gender, diagnosis and study centre.

<sup>b</sup>By study centre:

London

Alcohol use *versus* No alcohol use  
 Comorbid AUD *versus* No alcohol use  
 Nottingham  
 Alcohol use *versus* No alcohol use  
 Comorbid AUD *versus* No alcohol use

Unadjusted RR 0.617\* (0.450-0.844)  
 Unadjusted RR 0.740 (0.491-1.116)  
 Unadjusted RR 1.461 (0.766-2.786)  
 Unadjusted RR 1.432 (0.661-3.103)

\*p<0.05

### **8.6.2 Relationship between comorbidity and compulsory admission**

This section is concerned with unveiling the patterns of compulsory admission and therefore relates to the focus of the second hypothesis. As we saw in the previous section rates of hospital admission varied by ethnicity with rates in most groups actually being lower for patients with comorbidity; with the exception of Black Caribbean patients with comorbid drug use disorder and White patients with comorbid alcohol use disorder, where risk was higher than non-users.

For patients who had had at least one admission the number of those admissions that were under section on admission was calculated. A binary variable was created with patients who had no compulsory admissions scored as '0' and patients who had at least one compulsory admission scored as '1'. Binary logistic regression was used to explore the relationship between patients that had at least one compulsory admission and substance use.

All patients with drug use were 1.5 times more likely and patients with comorbid drug use disorders were over 2.5 times more likely to have had a compulsory admission over the follow-up compared to patients with no drug use (Table 28). After adjustment for a priori confounders these likelihoods were only slightly decreased (Drug use: OR 1.457, CI 0.739-2.872,  $p=0.277$ ; Comorbid DUD: OR 2.270, CI 1.003-5.135,  $p=0.049$ ).

As above, stratified analyses were conducted. With odds of roughly 1.5 of those of non-drug users, patients with drug use in both the London and Nottingham sample and comorbid drug use disorder in the London sample were more likely to have had a compulsory admission. However, patients with comorbidity in the Nottingham only sample were over four times more likely to have had a compulsory admission (OR 4.875, CI 1.400-16.973,  $p=0.013$ ). This was statistically significant, although

caution should be taken with this interpretation as the confidence intervals were wide.



**Table 28: Relationship between compulsory hospital admission, drug use and comorbid DUD**

Compulsory admission over the FU period	Never had compulsory admission	At least 1 compulsory admission	Unadjusted Odds Ratios	95% CI	p	Adjusted Odds Ratios <sup>a</sup>	95% CI	p
<b>Whole sample<sup>b</sup></b>								
No drug use	47 (56.6)	65 (40.9)	1.000			1.000		
Drug use	23 (27.7)	48 (30.2)	1.509	0.810-2.813	0.195	1.457	0.739-2.872	0.277
Comorbid DUD	13 (15.7)	46 (28.9)	2.559	1.244-5.262	0.011	2.270	1.003-5.135	0.049
<b>White British</b>								
No drug use	33 (56.9)	21 (32.8)	1.000			1.000		
Drug use	17 (29.3)	22 (34.4)	2.034	0.881-4.695	0.096	2.381	0.931-6.092	0.070
Comorbid DUD	8 (13.8)	21 (32.8)	4.125	1.547-11.002	0.005	4.435	1.398-14.062	0.011
<b>Black Caribbean</b>								
No drug use	10 (58.8)	21 (32.3)	1.000			1.000		
Drug use	4 (23.5)	22 (33.8)	2.619	0.710-9.655	0.148	3.103	0.699-13.773	0.136
Comorbid DUD	3 (17.6)	22 (33.8)	3.492	0.842-14.476	0.085	4.564	0.747-27.886	0.100
<b>Black African</b>								
No drug use	4 (50.0)	23 (76.7)	1.000			1.000		
Drug use	2 (25.0)	4 (13.3)	0.348	0.047-2.576	0.301	0.247	0.023-2.664	0.249
Comorbid DUD	2 (25.0)	3 (10.0)	0.261	0.033-2.089	0.206	0.117	0.009-1.602	0.108

CI, confidence interval.

<sup>a</sup>Adjusted for age, gender, diagnosis and study centre.

<sup>b</sup>By study centre:

London

Drug use *versus* No drug use  
Comorbid DUD *versus* No drug use  
Drug use *versus* No drug use  
Comorbid DUD *versus* No drug use

Unadjusted OR 1.442 (0.614-3.391)  
Unadjusted OR 1.607 (0.650-3.973)  
Unadjusted OR 1.517 (0.577-3.987)  
Unadjusted OR 4.875\* (1.400-16.973)

\* p<0.05

**Table 29: Relationship between compulsory hospital admission, alcohol use and comorbid AUD**

Compulsory admission over the FU period	Never had compulsory admission	At least 1 compulsory admission	Unadjusted Odds Ratios	95% CI	p	Adjusted Odds Ratios <sup>a</sup>	95% CI	p
<b>Whole sample<sup>b</sup></b>								
No alcohol use	14 (16.7)	33 (20.9)	1.000			1.000		
Alcohol use	61 (72.6)	95 (60.1)	0.661	0.327-1.334	0.248	0.649	0.303-1.388	0.265
Comorbid AUD	9 (10.7)	30 (19.0)	1.414	0.535-3.740	0.485	1.129	0.394-3.238	0.821
<b>White British</b>								
No alcohol use	9 (15.0)	4 (6.3)	1.000			1.000		
Alcohol use	44 (73.3)	45 (71.4)	2.301	0.660-8.023	0.191	1.925	0.527-7.031	0.322
Comorbid AUD	7 (11.7)	14 (22.2)	4.500	1.017-19.902	0.047	3.340	0.673-16.581	0.140
<b>Black Caribbean</b>								
No alcohol use	3 (17.6)	15 (22.7)	1.000			1.000		
Alcohol use	12 (70.6)	37 (56.1)	0.617	0.152-2.501	0.499	0.399	0.091-1.755	0.224
Comorbid AUD	2 (11.8)	14 (21.2)	1.400	0.203-9.662	0.733	0.998	0.134-7.419	0.998
<b>Black African</b>								
No alcohol use	2 (28.6)	14 (48.3)						
Alcohol use	5 (71.4)	13 (44.8)	-	-	-	-	-	-
Comorbid AUD	0 (0.0)	2 (6.9)	-	-	-	-	-	-

CI, confidence interval.

<sup>a</sup>Adjusted for age, gender, diagnosis and study centre.

<sup>b</sup>By study centre:

London	Alcohol use <i>versus</i> No alcohol use	Unadjusted OR 0.552 (0.224-1.358)
	Comorbid AUD <i>versus</i> No alcohol use	Unadjusted OR 2.023 (0.480-8.521)
Nottingham	Alcohol use <i>versus</i> No alcohol use	Unadjusted OR 1.734 (0.449-6.695)
	Comorbid AUD <i>versus</i> No alcohol use	Unadjusted OR 2.000 (0.384-10.409)

\*p<0.05

When likelihood of compulsory hospital admission was examined by ethnic group even more elevated likelihoods for compulsory admission were found. White patients with drug use were more than two times more likely and White patients with comorbid drug use disorders were more than four times more likely than non-drug users to have had a compulsory admission. These likelihoods held after confounders were adjusted for (Drug use: OR 2.381, CI 0.931-6.092,  $p=0.070$ ; Comorbid DUD: OR 4.435, CI 1.398-14.062,  $p=0.011$ ), however the confidence levels for both findings were very wide.

Similarly, Black Caribbeans with drug use were roughly 2.6 times as likely and Black Caribbeans with Comorbid DUD were 3.4 times as likely to have had a compulsory admission compared to non-drug users. After adjustment the likelihood for drug users was around three fold and the likelihood for patients with comorbidity was four and a half times the odds of non-drug users (Drug use: OR 3.103, CI 0.699-13.773,  $p=0.136$ ; Comorbid DUD: OR 4.564, CI 0.747-27.886,  $p=0.100$ ).

For Black Africans the likelihoods for compulsory admission were very different. Drug users were 0.34 times less likely to have had a compulsory admission over the follow-up (OR 0.348, CI 0.047-2.576,  $p=0.301$ ) and after adjusting for a priori confounders this decreased to 0.24 (OR 0.247, CI 0.023-2.664,  $p=0.249$ ). For Black African patients with a comorbid DUD the likelihoods of having a compulsory admission were even less at 0.26 the odds of non-drug users (OR 0.261, CI 0.033-2.089,  $p=0.206$ ) and after adjustment this reduced to 0.1 the odds of non-drug users (OR 0.117, CI 0.009-1.602,  $p=0.108$ ).

Patients who had alcohol use disorders were then investigated (Table 29). Firstly the whole sample was looked at. Patients with drug use were 0.6 less likely to have had at least one compulsory admission whereas patients with comorbid AUD were 1.4 times more likely (OR 1.414, CI 0.535-3.740,  $p=0.485$ ) than those who had never used alcohol.

After adjusting for a priori confounders the likelihood for drug users remained (OR 0.649, CI 0.303-1.388,  $p=0.265$ ), however the likelihood for patients with comorbidity was reduced to being almost equivalent to that of non-alcohol users (OR 1.129, CI 0.394-3.238,  $p=0.821$ ).

When stratified analyses were conducted the odds for having a compulsory admission in patients with comorbidity in both the London and Nottingham samples were twice that of patients that hadn't used alcohol. However, the odds for alcohol users in the London sample were 0.5 of non-alcohol users (OR 0.552, CI 0.224-1.358,  $p=0.196$ ) and 1.7 in the Nottingham sample (OR 1.734, CI 0.449-6.695,  $p=0.424$ ).

Numbers in the Black African group were too small to perform analyses and analyses for White patients and Black Caribbean patients were conducted separately. White patients with alcohol use were more than twice as likely to have had a compulsory hospital admission compared with non-alcohol users, while those with comorbidity were 4.5 times as likely. After adjustment alcohol users had similar odds but patients with comorbidity had slightly reduced odds (Alcohol use: OR 1.925, CI 0.527-7.031,  $p=0.322$ ; Comorbid AUD: OR 3.340, CI 0.673-16.581,  $p=0.140$ ).

Conversely, Black Caribbean drug users had a lower likelihood for compulsory admission (OR 0.617, CI 0.152-2.501,  $p=0.499$ ) and this decreased after confounders were adjusted for (OR 0.399, CI 0.091-1.755,  $p=0.224$ ). Black Caribbean patients with comorbidity were 1.4 times more likely to have had a compulsory admission compared to Black Caribbean patients that never used alcohol. However this was reduced to equal odds with non-alcohol users after adjustment (OR 0.998, CI 0.134-7.419,  $p=0.998$ ) although the result was not statistically significant and had wide confidence intervals.

In summary, the findings above show that the average number of hospital admissions differed between White, Black Caribbean and Black

African patients. With the exception of Black Africans, who had lower rates, patients with comorbidity had higher rates of hospital admissions than patients with no drug use. Although only Black Caribbean patients with comorbidity had higher rates after other sociodemographic and clinical variables were held constant. When looking at alcohol use disorders only White patients have higher rates of hospital admission compared to patients that had never used alcohol and Black African patients with comorbidity had significantly lower rates of hospital admissions.

In terms of the PhD research question, which hypothesised that regardless of ethnicity patients with comorbidity would have more compulsory admissions, it is clear from the above evidence that having a compulsory admission was significantly more likely in drug users as well as patients with comorbidity. However, as with other evidence, this was not the case for Black African patients who were less likely to have had a compulsory admission.

## **8.7 CONCLUSIONS**

As the findings above confirm, the hypothesis that the prevalence of comorbid substance use disorder in individuals with an eight year history of psychosis will differ according to ethnic group and that the prevalence of comorbidity will be higher in Black Caribbean, and lower in Black African, patients compared to White patients was only partially accepted when drug use disorders and alcohol use disorders were examined.

There was significantly less drug and alcohol use, as well as drug and alcohol use disorders in Black African patients compared to Whites and Black Caribbeans. Black Caribbeans did not have an increased prevalence of drug or alcohol use disorders.

Slightly lower rates of drug use and drug use disorders were found in Black Caribbean patients compared to White patients. This finding is similar to that of Cantwell et al., (1999), however prevalence rates were only marginally lower and these did not reach statistical significance. These findings may be explained by changing patterns in types of drugs used or alternatively by an increase in overall drug use disorders in psychiatric patients from a Black Caribbean ethnicity, which was estimated in UK studies in the late nineties and early 2000s at six to seven percent (Cantwell et al., 1999; Miles et al., 2003) but was found to be forty percent in this study. Moreover, it is interesting to note the differences in the prevalence of drug use disorders and alcohol use disorders in each ethnic group. Similarly to the early Cantwell et al. (1999) study, alcohol use was more prevalent in White patients and the likelihood for using alcohol and having an alcohol use disorder was considerably higher in White patients.

Although this study sought to test 'true' comorbidity (i.e. the presence of a diagnosable substance use disorder in addition to a diagnosis of a psychotic disorder), it was useful to separate out substance users from those that had substance abuse or dependence.

In relation to the second hypothesis (whether, regardless of ethnic group, comorbidity was negatively associated with psychotic relapse), we see that the findings do not support this hypothesis. Despite the finding that there wasn't a higher prevalence of comorbid substance use disorders in Black Caribbeans the study did observe increased likelihoods for having either an episodic course or a neither episodic nor continuous course type in Black Caribbean patients with drug use and comorbid drug use disorders although these findings were not statistically significant. This finding was not found in patients with alcohol use disorders however.

In addition, Black Caribbeans with comorbid drug use disorders were found to have higher rates of psychotic relapses, while Whites with comorbid drug use disorders had lower rates of risk. While the opposite is observed for Black Caribbean and White patients with alcohol use

disorders which may well be explained by increased the likelihood of alcohol use and alcohol use disorders in White patients.

Not surprisingly, Black Africans who had a low prevalence of both drug and alcohol use disorders had lower rates of psychotic relapse.

The last hypothesis was concerned with service utilisation. The average number of hospital admissions that patients had over the follow-up period differed by ethnic group. Additionally, after key sociodemographic and clinical variables were controlled for only Black Caribbean patients with comorbid drug use disorders had higher rates of hospital admissions than patients with no drug use and this did not reach statistical significance.

In line with the other findings in this study it was the White patients with comorbid alcohol use disorders that had higher rates of hospital admission compared to patients that had never used alcohol and Black African patients with comorbidity that had significantly lower rates of hospital admissions. This finding is in complete contrast to the preliminary findings by, Afuwape et al. (2006) as part of the UK COMO study which found higher levels of admissions in Black African patients with comorbidity.

With regard to the PhD research question, which hypothesised that regardless of ethnicity patients with comorbidity would have more compulsory admissions, it was clear from the evidence that having a compulsory admission was significantly more likely in drug users as well as patients with either type of comorbidity. However, as with other evidence, this was not the case for Black African patients who were less likely to have had a compulsory admission.

The next section of this thesis examines the findings from the qualitative arm of the study. I will revisit the findings from this phase of the study very briefly in next section. However, a full discussion of the

findings in both arms as well as the study limitations will be discussed in Chapter 10.

### Chapter Summary 8.

#### **Chapter Summary**

##### Aims of the Chapter:

To summarise and evaluate the findings from Phase One of the study (including prevalence , estimates of risk for comorbidity and the relationship between comorbidity and negative outcome) in relation to the PhD study hypotheses.

##### Key Points:

- The hypothesis that the prevalence of comorbid substance use disorders (SUD) in individuals with an 8-12 year history of psychosis differs according to ethnic group and that the prevalence of comorbid substance use disorders is lower in Black Africans compared to Whites was supported.
- Findings did not support the hypothesis that the prevalence of comorbidity is higher in Black Caribbeans compared to Whites.
- The second hypothesis that comorbidity is negatively associated with psychotic relapse and compulsory hospital admission was not supported.



## **CHAPTER 9: PHASE TWO RESULTS**

The analytical framework for Phase Two is summarised in more detail in Chapter 7. Briefly, themes relating to key areas of interest were identified through a process of detailed reading, annotating and categorising of interview transcripts and formed the basis of an initial coding framework. The analysis explored relationships between categories both within and between transcripts, which allowed differences and similarities between respondents from the three ethnic groups to be explored, thereby addressing the study research questions. Analysis was aided by use of the computer software package MaxQDA. The following chapter summarises the findings of the qualitative study. Where appropriate, brief summaries of each section of findings are given, including preliminary discussion of these findings in relation to the quantitative study findings.

### **9.1 ADDRESSING THE RESEARCH QUESTIONS**

This phase of the study, aimed to both describe if/how the problem of comorbidity differs for ethnic minorities in psychotic populations and to identify conceptualisations of illness and substance use. The following research questions were investigated:

- 1) How do individuals with comorbidity of psychosis and substance use disorders construct their experiences of 'psychosis' and drug and alcohol use 8-12 years after their first episode?
- 2) How do individuals with comorbidity of psychosis and substance use disorders construct their experiences of mental health and substance abuse treatment services?

- 3) What is the perceived role (if any) of family, friends and other social support networks in the treatment process for 'psychosis' and substance use disorder?

Before themes identified in accounts are described and interpreted it is important to detail here how the research questions were addressed through detailed analyses of the data. It is also important to detail as part of addressing the three research questions how patterns and typologies were uncovered in the data and in particular how these patterns are representative of this small sample of respondents only and generalisations beyond that should be made with caution.

#### **9.1.1 Describing the sample and interpreting the data**

This chapter is split into three main parts: Describing the characteristics of the qualitative sample; describing the devices and mechanisms (what the respondents were doing in their accounts) that the respondents used to construct their experiences; and describing the themes (what the respondents were saying in their accounts) that respondents used to construct their experiences.

Describing the sample and its characteristics is the first sub-section in the main body of the findings of the qualitative study. Here a summary of the sociodemographic and clinical characteristics of AESOP patients who were identified as eligible for the qualitative study is given as well as the number and type of subsequent exclusions that were made. Next, the chapter moves onto a description of the devices and mechanism that the respondents in the final qualitative sample used to describe their experiences and ultimately show us 'how' they gave their account and constructions. The final part of the chapter summarises the themes that became apparent after detailed analyses of the content of the accounts, as well as a discussion of the relationships (typologies) between the account themes and the respondents sociodemographic and clinical

characteristics (and other categorical descriptors used to create typologies). Finally interpretation of the account devices, themes and typologies are discussed in relation to the research questions and findings from phase one of the PhD study.

### **9.1.2 Answering the 'how'.**

'How' respondents constructed their experiences has been addressed in two ways; the first part of addressing the 'how' was to describe the more latent (see section 7.2) aspects of how people with a long history of psychosis and substance use disorders construct their experiences. The 'how' is described in terms of the mechanisms and devices which respondents use to describe their experiences. They are an analysis of what people are doing in an account rather than just what they are saying (Silverman et al., 1993). In other words uncovering the frameworks which they use to create their account not only lends toward a better understanding of how accounts are created but also serves as foundational elements in attempt understand the content of the accounts (what they are saying).

The second part of addressing the 'how' in how individuals construct their experiences involve looking at the content of the accounts; finding similarities in categories and themes themselves and then by the characteristics of the respondents. This is uncovering what people are saying in their account, (what their constructions are rather than how they do it) and comprises both the latent and manifest aspects of talk.

### **9.1.3 Interpreting talk: Creating themes**

The topic guide was semi-structured; a list of questions was used to guide the interview, but there was room for follow-up or probing

questions when respondents appeared unable (through lack of recall) or unhappy (through lack of rapport or embarrassment) to give detailed answers, as well as to encourage elaboration of interesting comments.

Broadly, these questions were asked of all respondents:

- How respondents defined their ethnicity
- What had lead them to make contact with mental health services the first time
- Whether they had experienced any difficulties around that time
- Whether their family or friends were involved in their contact with mental health services
- How they felt when they experienced those difficulties
- Did they think they needed help
- When did they first start using drugs or alcohol
- Have they ever used substances more or less frequently and why
- What were their experiences of mental health services or drug treatment services
- Did the respondent find mental health services/drug treatment services involvement useful

Additional follow-up questions were asked to gauge more detail of events and perceptions. Below is an example of how an initial question (asking whether the respondent was put on a section during his first admission to a mental health hospital) lead to further questioning (using probes, prompts and encouragement) on the details of that admission:

QS3 Lines 222-241 (Male, White)

Int: Were you ever put on a section when you were there?

Resp: No.

Int: No.

Resp: It was just standard stuff of you know first week or what have you in the ... and stuff like that so.

Int: Yeah and how, how was that experience how did you find that?

Resp: Weird.

Int: Yeah.

Resp: It was it was it was quite full on.

Int: How do you mean?

Resp: Well it was going into, into, into a you know an admissions ward where there were people there that were ill and stuff and they've got different issues and so it was quite a quite a and living there for three months you know it was quite a quite a unusual experience at first but you get used to it and I and I started getting back to being myself again you know and gradually little bits were coming out and I was like you know everyone knows everyone knows me sort of thing in there and that.

Int: Yeah.

Resp: Got on well with most people and stuff.

Int: Did your mum come and visit you regularly?

Resp: Yeah and my dad would come down as well sometimes.

Int: Yeah.

Resp: Yeah you know and I remember the first day going out you know well the first the first step was the step of leaving the ward on my own was just to go to the go the, the canteen on site.

Int: Yeah.

Resp: And get a drink and then come back and stuff that was the first sort of step and.

Int: And gradually it became more.

Resp: Yeah.

The topic guide also allowed the researcher flexibility to adopt the respondents' language to clarify questions as well the flexibility to use other forms of questioning to illicit accounts about events that were sensitive (e.g. asking questions about criminal activity).

The above extract is an example of how it was not always appropriate to map categories and themes onto the interview questions (for example mapping this extract to a theme called 'experience of first contact with services'). This extract of data as well as other contextual data relating to the experiences of this respondent's first admission (either located immediately around this extract or elsewhere in the account) can be used to create several themes. These include: experiences of hospitalisation; involvement of family members during the treatment process; perceptions of similarities and differences between the respondent and other patients; and mastery in the treatment process.

As with normal organic talk people tend to elaborate or shut down to questions and often construct answers in a way that makes sense to them and not necessarily in the same way that the questioner has conceptualised or asked the questions. In addition, as we discussed in Chapter 7 salient themes can be disentangled from the latent aspects of talk, giving us hints and signs about how people frame their experiences and the world in general.

With that in mind, the categories and themes created from each stage of the analyses bear more relationship to the content of the interviews (the data) than the interview topic guide (the instrument used to collect the data). In this way categories and themes correlate more closely with the interviewees conceptualisations of the world and not the interviewer's pre-conceptions of illness experience which will no doubt be represented by the types of questions that were and were not asked.

#### **9.1.4 Prompts, probes and encouragement**

Prompts, probes and encouragement are features of semi-structured interviewing as was touched on in section 5.7. They are considered common processes in conducting interviews and the significance of them is arguably overlooked in the analysis of interview accounts. It was evident from the interview data for this study that not only were prompts and probes used but they were needed to open up discussion points and elicit more detail. However, they went toward creating and reinforcing many of the account mechanisms used in the interviews and themes elicited from the accounts. In other words, they exemplify how 'an account' is a co-creation between interviewer and respondent.

While the account mechanisms and themes described below are those often created by respondents who were trying to construct experiences of illness, drug use and treatment (or more accurately this group of respondents) and on many occasions came in the form of detailed and coherent talk (i.e. there was no or limited need for prompts and probes), they were also an illustration of account giving which was more heavily directed by the interviewer (i.e. prompts and probes were required to expand talk). Unprompted responses can be considered to be more accurate constructions of events than those given in response to an interviewer's questioning (National Institute of Justice, 2013).

In addition, distinguishing between prompted and unprompted responses can be a useful way of determining what is 'most' salient to the interviewee as was demonstrated in a New Zealand Ministry of Health commissioned study investigating youth knowledge and attitudes towards mental illness where they categorised 'top of mind' responses from prompted responses (Fearne et al., 2006).

The discussion of the account themes that form the body of the results section for this arm of the study includes examples in both these two instances and so can, albeit crudely, grouped into 'prompted' and 'unprompted' themes. Prompted responses were considered to be responses to direct questioning about a topic. Unprompted responses on the other hand were responses that occurred when the respondent was giving descriptions of events or perceptions that did not directly relate to the preceding question or could be considered additional information. When estimations of prompted and unprompted forms of themes have been given these are based on the primary (the first instance the thematic response was elicited in the account) responses of the respondent (respondents often gave prompted and unprompted responses on the same topic within their account). In this way we can see which themes were of most salience in each of the respondent's constructions.

#### **9.1.5 Creating typologies: Uncovering the different roles of the social actor**

As discussed in Chapter 7 part of qualitative analysis is uncovering patterns in the data. This can be done using quasi-statistical methods Dey (1993). The qualitative computer analysis package MaxQDA was helpful for this very purpose. Along with the typical a priori variables of interest (for example gender and ethnicity) other categorical variables were created from codes that were used to describe categories and themes. These variables were then used to generate frequencies and even to cross-tabulate categorical variables with sample characteristics. The categorical variables were then used to explore connections within the data (Dey, 1993). This formed the basis of identifying typologies within the data.

It should be noted that the numbers in the final sample were far too small to perform formal statistical tests such as chi square, however



summarising the frequency in which a theme was used by respondents with particular characteristics can give us a picture of how certain types of respondents construct illness and drug use experiences in certain ways. As well as gender and ethnicity, variables used in the first arm of the study were also used to create typologies of constructions. These included:

- Age
- Diagnosis
- Type of substance use disorder
- Whether the patient was in remission from their first episode
- Whether the patient had had a compulsory admission to hospital

The variable 'family history' (whether a respondent described in their account having a family member who had experiences and/or been treated for a mental health problem) was also noted and used as a variable for comparison. In addition to the above sample characteristics there were several themes that emerged within accounts during the analyses that subsequently became categorical variables. These categorical variables related to the roles within which the respondents put themselves during the interview and provided additional characteristics with which comparisons could be made.

#### **9.1.5.1 I have a mental illness**

The first theme that was used to create typologies of constructions of illness, substance use and experiences of treatment services was related to whether respondents (despite having a psychiatric diagnosis) felt they had a mental illness. One of the primary aims of the qualitative study and the first research question was how people with comorbidity construct their experiences of psychosis. This question, in part, relates to whether people with comorbidity categorise their experiences as a mental disturbance or if they use another framework of understanding. The term 'experiences' which was used during the interview, was considered more

neutral than 'mental illness' and allowed respondents to identify their experiences using a broader framework than that of psychiatry.

Further unpacking of what respondents believed constituted 'a mental illness' is looked at in the main body of the results, but here this theme around whether a respondent saw themselves as having a mental illness or not was used to crudely categorise respondents. The category 'I have a mental illness' (along with the categories described below) was useful for looking at patterns of constructions between different types of respondents (for example whether respondents who constructed their experiences as a mental illness were more prominent in a particular ethnic group or whether drug use as a cause of experiences was found more frequently in respondents who did not see their experiences as a mental illness).

Respondents were directly asked during the interview if they felt their experiences constituted a mental illness. A number of respondents also gave unprompted indications of whether they constructed their experiences in that way. Both types of responses were coded as either viewing themselves as having a mental illness or not.

Additionally, using the lexical search function in MaxQDA, instances where terms such as 'mental illness', 'depression', 'breakdown' and all other terms used by respondents to describe their experiences (see section 9.4.1.1) were found and coded (including the relevant talk around the term) into one of these two categories if appropriate. Because counting instances of the appearance of a code is a crude way to measure subjective construction, and for additional accuracy, each coded segment (both prompted and unprompted responses as well as coded segments from the lexical search) was reviewed a second time and then each respondent was categorised as falling primarily into one of three category levels (I did not have/do not have a mental illness; I have/had a mental illness; or undefined) using two criteria:

- 1) the number of instances each category level appeared in an account (using the 'transform code into categorical variable'

function in MaxQDA which transforms sub themes under a larger theme into levels of a categorical variable and then counts instances each level appears in the whole document) and which category level had majority and;

- 2) the overall impression of 'self', 'mental illness' and construction of experiences given by the respondent in the account as a whole. Thirty-seven percent of respondents gave an overall construction of their experiences as having had a mental illness or that they currently had a mental illness.

QS19 Lines 601-605 (Male, Other)

Int: Well the question was do you think it is an illness? So do you think bipolar is a mental illness I suppose?

Resp: Yeah.

Int: You do?

Resp: Yeah because I don't know what dementia is but I think it could be like similar to dementia.

The respondents that were categorised as 'undefined' gave mixed or incoherent conceptualisations of their experiences in relation to mental health. Or as is evident in the following extract a response of not having a perception.

QS12 Lines 273-277 (Male, Black African)

Int: Did you, at the time when you went into hospital, did you feel that you had a mental illness? Or what did you feel was wrong?

Resp: I never thought about it.

Int: No?

Resp: No. Never made any sense when I was thinking about it. I never really thought about it as such.

**Table 30: Perceptions of mental illness experiences**

	<i>n</i>	%
<b>Perception of experiences (n=19)</b>		
I did not have/do not have a mental illness	6	31.6
I have/had a mental illness	7	36.8
Undefined	6	31.6

A number of respondents (n=3) who did not believe they had a mental illness did however believe that they had been suffering from depression (which was not considered to be a mental illness).

#### **9.1.5.2 I have a problem with substances**

The second theme that was used as a categorical variable was whether a respondent felt they had a problem with substances. This theme was not as clear cut as the above theme as 'problem' could be defined in many ways including:

- the frequency with which a substance was used,
- the amount that was used when using,
- any withdrawal problems encountered when not using the substance
- any problems with the law or social relationships as a consequence of using a substance
- simple 'addiction' which may have included some or all of the above (the concept of addiction is unpacked in more detail in later sections)

One of the other primary aims of the qualitative study was to uncover how people with comorbidity construct their experiences of substance use. This question, in part, relates to whether people with comorbidity categorise their use as acceptable or as a cause for concern for either themselves or others around them. This theme, turned categorical variable, was used as a respondent characteristic to highlight

patterns and relationships between types of respondents and themes used in accounts.

Respondents were directly asked during the interview if they felt they had a problem with each of the substances they talked about during the course of the interview or if they had ever sought help for their substance use. In addition a number of respondents gave unprompted indications of whether they constructed their substance use as having been or currently being problematic. Both types of responses were coded as either viewing themselves as having a problem with at least one substance or not. The same process that was detailed above (for mental illness) was used to code relevant data into one of these two categories and then make a judgement as to which category the respondent fell into overall.

**Table 31: Perceptions of substance use experiences**

	<i>n</i>	%
<b>Perception of substance use (n=19)</b>		
I do have a problem with substance use	11	57.9
I do not have a problem with substance use	4	21.1
Undefined	4	21.1

Nearly sixty per cent of the sample of respondents considered themselves to have had or have a problem with at least one of the substances they had mentioned using. Interestingly, as we can see from the following extract problematic use or addiction in all but one of the respondents that believed they had a problem with substances was explicitly stated.

QS16 Lines 517-519 (Female, Black Caribbean)

Int: Have you ever wanted to stop completely?

Resp: I'm definitely addicted to it but I could never just put it down and say

“Right I’m never going to smoke again”. I think personally I think to myself “I want to die. I’m going to be really ill”. People say “It’s not heroin you know. Come on it’s just weed” and I’m like “No you don’t know what it’s like. I’ve been smoking for years. You don’t know what it’s like”.

### 9.1.5.3 The relationship between substance use and experiences

This arm of the study only included current or past psychiatric patients who had suffered from psychosis as well as a substance use disorder. Subsequently detailing the relationship between the mental illness experiences and substance use was of utmost concern. With that in mind a theme around this relationship was coded for in accounts and transformed into a categorical variable. Questions concerning the relationship between experiences (whether they defined them as a mental illness or not) and substance use were directly asked in the interview and prompted and unprompted responses relating to views on this relationship were identified and coded within accounts. Both problematic use and use not considered problematic were examined.

Using the process described above respondents overall constructions of the relationship between their mental illness experiences and substance use (drug and alcohol) were grouped into one of three categories; Substance use is not related to my mental health; Substance use is related to my mental health and; undefined.

**Table 32: Constructions of the relationship between experiences and substance use**

	<i>n</i>	%
<b>Perception of substance use (n=19)</b>		
Substance use is not related to my mental health	2	10.5
Substance use is related to my mental health	15	78.9
Undefined	2	10.5

Nearly eighty per cent of the respondents (n=15) expressed that they saw a relationship between the substances that they used and/or had a problem with and the experiences that lead them to into contact with mental health services. The majority of these respondents' constructions clearly conceptualised this, as in the exemplified below.

QS6 Lines 385-386 (Male, Black Caribbean)

Int: And when you've had periods where you've wanted to stop smoking, could you tell me why, what has been your main reasons for wanting to stop?

Resp: Paranoia was the main reason. Because I'm on medication as well, and I've been prescribed as mentally ill. Suffering from schizophrenia. So I thought to myself "It could make it worse than what it already is." And because I was going through the depression at the time they were saying to me "Oh if you smoke, the medication's not going to work."

#### **9.1.5.4 Other patients and otherness**

Whether a respondent considered themselves to be the same (i.e. suffering from the same or similar mental illness or experiencing the same type of things that other patients had) or different (i.e. not experiencing the same things or having the same diagnosis) from other patients they came across in hospital and community services was an important construction in most accounts.

Questions relating to these similarities and differences were asked of respondents during the interviews; however there were many instances where this self-categorisation was offered unprompted in accounts. Severity of illness was one way in which respondents created distance between their own experiences and the experiences of other patients; by creating a 'me' and 'them' dichotomy. Negative terms or

extreme forms of terms used to describe others in the following extract is an example of how one respondent created this dichotomy.

QS7, Lines 312-315 (Male, White)

Int: What did you before you went into hospital and you have talked about this a little bit, what did you think about mental illness? What did you know about it already?

Resp: I didn't, I don't know, I suppose I was probably like a lot of other people. Like people were literally like lunatics; proper mad people, they need to be locked away because they're dangerous people. I don't know I sort of like everybody that's, I've got a mate who's probably a severe schizophrenic I think that was the only kind of definition back then. People didn't even really talk about depression. There wasn't so much associated with being in the mental hospital. It was just like you're a paranoid or a delusional schizophrenic and those sort of people will mash you up if they see you. Do you know what I mean? It just totally was but I do remember being in the car and there was sort of like, "What am I going to be going into?"

How respondents situated themselves in relation to other patients was coded and categorised using a similar process for creating categorical variables detailed above. Respondents were grouped into one of four category levels: I am different from other patients; I am the same as other patients; no opinion expressed; undefined.

This self-categorisation was used to compare other themes and constructions within accounts along with the other categorical variables discussed above. Only 2 of the 19 respondents conceptualised themselves as being the same or similar to the other patients they saw in hospital or in community services. Whether a respondent felt that they were the same or different from other patients can be seen as related to how they constructed their illness and recovery process.



**Table 33: Perceptions of self**

	<i>n</i>	%
<b>Perception of self (n=19)</b>		
I am different from other patients	9	47.4
I am the same as other patients	2	10.5
no opinion expressed	3	15.8
undefined	5	26.3

Interestingly there was an equal spread of perceptions self among men, however all of the female respondents saw themselves as different from other patients.

## **9.2 PHASE TWO SAMPLE CHARACTERISTICS**

Having discussed the ways in which the qualitative data was used to address the research questions and how categories of sample characteristics were generated from account theme to help create typologies of experience in the above sections we now move on to the first part of the main body of the results section. This section describes the respondents. Here patients that were included and excluded from the final sample are discussed and compared by sociodemographic and clinical, characteristics.

### **9.2.1 Final sample characteristics and comparisons with AESOP data**

Nineteen patients were interviewed for the second phase of the PhD study. As discussed in Chapter 6 these patients were sampled from the AESOP follow-up study sample.

Table 34 compares the sociodemographic and clinical characteristics of AESOP patients with a diagnosis of comorbid substance use disorder (either drug/alcohol abuse or dependence) that were either excluded or defined as subject to attrition from the qualitative study to those that were included in the final sample and interviewed. As is often the case in comorbid psychosis and substance misuse populations (Addington & Addington, 2007; Donoghue et al., 2011; Larsen et al., 2006; Sevy et al., 2009) there were more men than there were women in the eligible sample and subsequently the final sample included more males. Similarly patients recruited to the qualitative study tended to be of younger age at their first episode of illness which is often the case for comorbid substance abusers in psychotic populations (McCleery, Addington & Addington, 2008). There were no significant differences between AESOP cases that were included and excluded from the qualitative study.

Table 35 summarises the sociodemographic and clinical characteristics of the final qualitative sample. There were small numbers of Black African and Other ethnicity cases in the eligible sample and so it was difficult to recruit adequate numbers of respondents in these ethnic groups to the final qualitative sample. There were no female respondents or respondents in the older age category for Black African or respondents from other ethnic groups. Equally Black African respondents all had an AESOP diagnosis of a schizophrenic disorder and comorbid drug use disorder.

In addition to the above there were a number of other differences within the final qualitative sample. Eight participants were interviewed in a home or social setting, five were interviewed in a psychiatric hospital or community health team, five were interviewed at the Institute of Psychiatry and one was interviewed in prison.

**Table 34: Phase Two interviewees by sociodemographic and clinical characteristics of AESOP Follow-up**

	<b>Interviewed (n=19)</b>		<b>Not interviewed (n=37)</b>				
<b>Follow Up</b>							
	<i>n</i>	<i>M (SD)</i>	<i>n</i>	<i>M (SD)</i>	<b>df</b>	$\chi^2$	<b>p</b>
AVERAGE LENGTH OF FU (YRS) <sup>a</sup>	18	9.73	37	8.79	1	0.837	0.360
<b>Sociodemographic Variables</b>							
	<i>n</i>	<b>%</b>	<i>n</i>	<b>%</b>	<b>df</b>	$\chi^2$	<b>p</b>
GENDER							
Men	14	73.7	30	81.1	-	-	-
Women	5	26.3	7	18.9			
ETHNICITY							
White British	7	36.8	19	51.4	3	4.036	0.258
Black Caribbean	7	36.8	8	21.6			
Black African	3	15.8	2	5.4			
Other	2	10.5	8	21.6			
AGE GROUP AT BASELINE							
16-29	15	78.9	26	70.3	1	0.482	0.488
30-65	4	21.1	11	29.7			
<b>Clinical Variables</b>							
DIAGNOSIS <sup>a</sup>							
Schizophrenia	12	63.2	28	77.8	2	1.424	0.491
Mania	4	21.1	4	11.1			
Depression	3	15.8	4	11.1			

<sup>a</sup>1 missing case

**Table 35: Final Phase Two sample by sociodemographic and clinical characteristics and AESOP ethnicity**

	White (All) (n=7)		Black Caribbean (n=7)		Black African (n=3)		Other (n=2)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
<b>Sociodemographic variables</b>								
GENDER								
Male	5	71.4	4	57.2	3	100.0	2	100.0
Female	2	28.6	3	42.8	0	0.0	0	0.0
AGE GROUP AT BASELINE								
16-29	4	57.1	6	85.7	3	100.0	2	100.0
30-65	3	42.9	1	14.3	0	0.0	0	0.0
<b>Clinical variables</b>								
DIAGNOSIS								
Schizophrenia	4	57.1	4	57.1	3	100.0	1	50.0
Mania	1	14.3	2	28.6	0	0.0	1	50.0
Depression	2	28.6	1	14.3	0	0.0	0	0.0
REMISSION								
Remission from 1 <sup>st</sup> episode	6	85.7	2	28.6	1	33.3	0	0.0
Subsequent episodes of illness	1	14.3	5	71.4	2	66.7	2	100.0
COURSE TYPE <sup>a</sup>								
Episodic	5	71.4	3	42.8	1	50.0	1	50.0
Continuous	0	0.0	2	28.6	0	0.0	0	0.0
Neither	2	28.6	2	28.6	1	50.0	1	50.0
DRUG ABUSE/DEPENDENCE								
Drug use disorder	6	85.7	3	42.9	3	100.0	2	100.0
Drug and alcohol use disorder	1	14.3	4	57.1	0	0.0	0	0.0

<sup>a</sup>1 missing case

### **9.2.2 Constructions of ethnicity**

As discussed in Chapters 1 and 3 constructions of ethnicity are contentious and often based upon the salience of complex socio-cultural and religious beliefs (Singh, 1997).

Although detailing constructions of ethnicity was not a primary research question of the qualitative study, it became clear that illuminating participant's constructions of their ethnicity might play a part in understanding their constructions of their illness. It was found in the quantitative study that there were differences in the prevalence of comorbid drug use disorder between Black African and White patients, but not between Black Caribbean and White patients. Differences in negative outcomes (for example, frequency of relapse and number of psychotic episodes) were found between Black Caribbean and White patients with comorbid substance use in the quantitative arm of the PhD study.

However differences in prevalence of drug and alcohol use disorders between Black Caribbean and White patients were not found. It would have been useful to examine whether differences in AESOP ethnic categorisation (which grouped mixed parentage patients in Black ethnic groups and did not account for place of birth) and the qualitative interview self-categorisation of ethnicity might go some way to explaining the lack of differences in prevalence. As we saw in section 3.3.1 a UK study looking at ethnic differences in comorbid psychosis and substance use disorder (Afuwape et al., 2006) found that the Black Caribbean and White patients had similar prevalence of cannabis and stimulant abuse; however, British Black patients had significantly higher prevalence's in both substances than Caribbean's and White patients.

Table 36 compares categorised self-ascribed ethnicity used in the AESOP study (used for sample selection) with the in-depth self-ascribed ethnicity documented during the course of the qualitative interviews. This

table highlights differences between the crude categorical groupings of ethnic minorities used in the analysis in first quantitative arm of this study and how they perceive themselves in relation to their ethnicity, nationality, colour and religion.

As we can see, one of the Black African respondents and over half of the Black Caribbean respondents considered themselves to be Black British or Mixed Black and White parentage. The majority of the Black respondents were British born but the differences described here are based on their own conceptualisation of ethnicity rather than just their place of birth.

Most respondent's constructions fell into the same categories as their AESOP ethnic groupings. The main differences were where respondents considered themselves to be 'mixed-race' and where geography or nationality played a part in their constructions (e.g. Black British).

Unfortunately because of low numbers in each ethnic group in the qualitative study it was difficult to uncover possible reasons for this lower than anticipated prevalence of substance use disorders in the first arm of the study. However, it was useful to look at respondents' constructions of ethnicity, particularly in relation to place of birth or self-defined nationality.

**Table 36: Final Phase Two sample by qualitative interview self-ascribed ethnicity and AESOP ethnicity**

	<b>AESOP categories used in quantitative PhD study</b>							
	<b>White (All) (n=7)</b>		<b>Black Caribbean (n=7)</b>		<b>Black African (n=3)</b>		<b>Other (n=2)</b>	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
<b>Qualitative constructions</b>								
White	1	14.3	-	-	-	-	-	-
White British	3	42.8	-	-	-	-	-	-
British/English	1	14.3	-	-	-	-	-	-
Celt	1	14.3	-	-	-	-	-	-
Black	-	-	-	-	1	33.3	-	-
Black British	-	-	2	28.6	-	-	-	-
Black African	-	-	-	-	1	33.3	-	-
Black Caribbean/Afro-Caribbean	-	-	3	42.8	-	-	-	-
Mixed/ half and half	-	-	2	28.6	1	33.3	1	50.0
Rastafarian	1	14.3	-	-	-	-	-	-
Eastern Asian	-	-	-	-	-	-	1	50.0

### **9.3 ACCOUNT DEVICES**

Ethnomethodologists such as Dingwall (1997) have argued that all social interaction (including interviews) can be seen as a 'dance of expectations'. Citing Goffman (1959 & 1983), Dingwall proposed that social interactions can be viewed as opportunities to manage others' impressions of them and each party will strive to present themselves as competent and sane to the other (Goffman, 1959 & 1983 cited in Dingwall, 1997). It is not surprising then that when interviewing people who have had, in psychiatric terms at least, a 'mental illness' examples of what Baker calls membership categorisation is produced during the account giving (Baker, 1997).

Membership categorisation relates to the roles we as social actors ascribe ourselves to. For example 'the mother' or the 'teacher' or most commonly in medicine 'the patient' and 'the doctor'. The membership categorisations used in the linguistic exchanges of the researcher and the mental health patient, are that of the 'sane' person or indeed the unwell or recovered person, with both parties subscribing to the membership of the sane person category or role during different points of the interview. Interestingly in this way roles are not only linguistically fulfilled but created within the interview experience by both the interviewee and the interviewer.

Additionally, respondents may feel obliged to display competence in the role of the 'interview respondent' (Murphy et al., 1998). For Dingwall this desire to demonstrate competence as a interview respondent or whatever role the interviewer has cast them in, is one of the reasons why interviews must be treated as an 'account'; a representation of the respondent's attempt to present themselves as a competent member of a particular community, rather than a literal description of the respondent's reality (Dingwall, 1997).

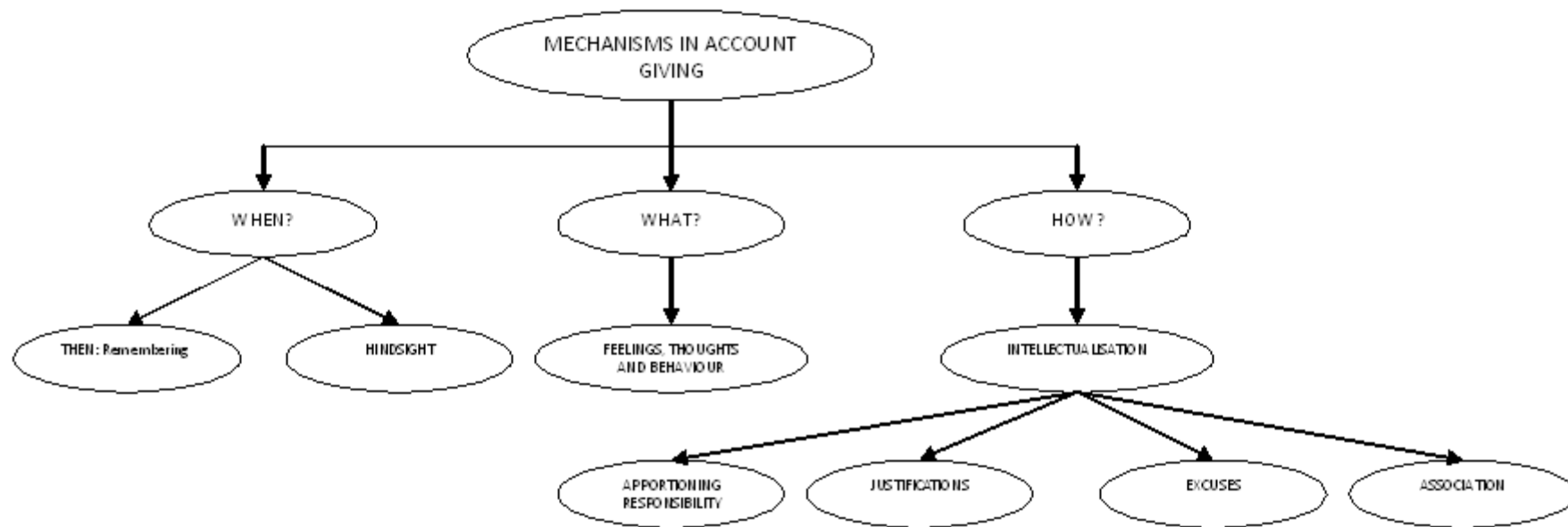


Although categorisation of how accounts are given or what social roles are ascribed to during the interview (Baker, 1997), was not a primary objective (i.e. was not a research question for this arm of the PhD study) it was clear when analysing the interview transcripts that 'how' a respondent constructed their experience could be answered in part by identifying the way they framed or presented their constructions (i.e. what the respondents were doing in their accounts). Moreover, during the analyses of the accounts certain types of mechanism or account devices seemed to be used by all the respondents in their accounts whereas some account devices were used by only some of the respondents.

Analyses of these frameworks can be viewed as one way of uncovering the moral and cultural assumptions that a respondent holds, what the most salient aspects of an event are as well as an illustration of the simple ways in which the respondent could increase researcher understanding of a concept or direct the interview to or away from a particular event. They are also useful in understanding how people with comorbid psychosis and substance use give accounts and create understanding of their experiences.

Figure 16 shows a schematic of the mechanisms uncovered during analysis. These mechanisms were categorised and can be grouped into three distinct areas: 'When' in time is the respondent locating their account; 'What' feature of the event is it that the respondent is describing and focusing on in their account; and 'How' (i.e. using what device or through what lens?) are they creating or giving the account of that event? Each of these areas was then subdivided again into themes that ran through the whole interview and categories located within specific sections of interviews.

**Figure 16: Model of the mechanisms used in account giving**



### 9.3.1 When

The account mechanism 'When' was split into two sub-thematic mechanisms: 'Then', which focused on whether a respondent specifically highlighted remembering (or not) an event; and Hindsight which was defined as the respondent constructing an understanding of an event (or specific features of an event), with knowledge acquired after the event had happened.

The sub-thematic account mechanism 'then' was based around the concept of remembering. The structure of the topic guide, as is the way with semi-structured interviewing, meant that respondents were asked initially to describe an event (for example and illness episode) and then as discussed above, probing questions were used to illicit more detail about how the respondent felt about that event or what other things had happened around that event. Sometimes this included asking the respondent what they remembered about an event.

However, there were many occasions in the accounts where respondents spontaneously directed (i.e. unprompted) the researcher to a memory. The sub-thematic mechanism 'then' is defined by its appearance only in unprompted responses; for example, in interview QS2 the respondent talked about the information she was given by the staff on the causes of her manic symptoms while in hospital. She was not asked directly by the interviewer if she could remember the event. However much of her description of the event was framed around the fact that she did not remember much except one exchange between her and a psychiatrist. This she detailed remembering 'perfectly'.

One of the male respondents used this mechanism in a similar way to describe him seeking help for his experiences.

QS4: Line 64-71 (Male, White)

Int: So did you go she took you to a GP to begin with?

Resp: Went to the GP in Streatham Hill I'd again at that point didn't really even know couldn't didn't have the conception of or the idea that it was the drug I was just fucked.

Int: Yeah.

Resp: I was you know and he sat me down he said have you been taking any drugs and I said yeah loads and it was then.

Int: Yeah.

Resp: That I kind of went ah that could be it.

Int: Yeah.

Resp: And ... that because I, I remembered very clearly going in and the receptionist saying what do you want to see a doctor for.

Six respondents used this mechanism at least once in their accounts and two used it on more than three occasions. Account giving is framed in the past, where past events and experiences are described. However respondents can signpost us both intentionally and unintentionally to details about the event that are salient to them. It became apparent from further analysis that 'remembering' was a useful tool. Firstly the respondent could highlight an event (for example feeling a particular way or doing a particular thing) by stressing the fact that they recalled it.

While many respondents seemed to aim to create clarity and coherence in their accounts, some respondents used recall, or more specifically the lack of recall as way of justifying gaps, lack of detail and coherence. In addition lack of recall which would most commonly be viewed as an impediment in their cognition because of the time in between the event occurring and the attempt to recall it, could also be because of mental disturbance at the time of the event, confusion due to

sedative medication at the time of the event or simply discomfort with the interview question.

Related to but separate from the mechanism around remembering was the mechanism 'hindsight'. This mechanism was considered to have been used when the respondent had framed their account of an experience or event within their current understanding of that event compared with their retrospective understanding of that event.

For example those who spoke about whether they needed to be in hospital may have described believing (what they thought or how they felt about the event) at the time of hospitalisation that they were not 'unwell', but they may also retrospectively believe the opposite to be true. Similarly a respondent may have described a particular reason (or lack of) for their drug taking at the time of using (for example taking drugs because they were available to them), but may retrospectively describe the reasons or causes of that experience in a different way (for example looking back at their drug use they see it was a coping mechanism).

This mechanism was represented in the accounts by two distinct types of responses. The first was 'I did not agree then but I do now'. This theme was evident in 12 of the 19 interviews and included instances where, for example, a respondent felt that they did not agree with their diagnosis or treatment or did not know they needed treatment at the time but they do (now on retrospect) agree with it or understand it now. The respondents talked about their treatment experiences and they framed these experiences as what they thought then in comparison to what they think now. For example, in seven interviews, going into hospital was seen as something that was done to them (which was related to themes around power and control in treatment), and the benefits were nearly always seen retrospectively.

QS7: Lines 316-317 (Male, White)

Int: Did you feel like you needed to go into hospital that first time?

Resp: I probably didn't know I needed to. Now I know I did need to yeah but I don't think I thought. Well I don't think I would have probably, I don't know what would have happened if I didn't because I was going down a pretty destructive path. But I wasn't happy about being in there when I first got there. And then like I say, I don't know what it was like I was given but once I'd sort of come to and stuff I did feel pretty relaxed being in there. And I'd got used to it.

The other thematic representation of the hindsight mechanism was 'I did not know at the time anything was wrong'. This theme was categorised by instances when respondents thought at the time of their experiences that they were fine or nothing was wrong with them (either in terms of their mental health or drug use). Although this theme incorporates elements of 'I did not agree then but I do now' it represents a slightly different linguistic way of expressing hindsight.

QS2: Lines 155-157 (Female, White)

Resp: But I wasn't aware at the time at all that this was happening no not at all.

Int: Right that you didn't think that there was anything wrong.

Resp: No absolutely not no.

Account giving relies on accurate or at least perceived accuracy in the recollection of an event. For the respondents interviewed in this study, these events may have covered over ten years of their life. Hindsight was one of the strongest thematic mechanisms observed in the accounts, however some respondents offered restricted responses requiring more direction and clarification from the interviewer (i.e. prompts or probes were used).

### 9.3.2 What

As mentioned before the structure of the topic guide meant that respondents were asked initially to describe an event and then probing questions were used to illicit more detail. As discussed in Chapter 7, often the language used by the interviewer (how did you feel?; tell me what was happening around that time?), was mirrored in the respondents responses. Despite this there were many occasions in the accounts where respondents spontaneously offered descriptions of how they were feeling or what they did in addition to one-dimensional or chronological accounts of events.

Respondents described their experiences in terms of how they felt about an event, what happened or what they did. For example, respondents may have described how they felt about the experience of being hospitalised (such as evoking feelings of anger or loss of control). Alternatively they may have described the experience of hospitalisation by time-lining and describing the process they experienced (e.g. a parent called the GP, then an ambulance arrived). All respondents used a combination of these descriptive methods and often interchangeably however they weighted them differently. This weighting gives us insight into the salient features of an experience for that respondent.

For some respondents, there were differences in the amount of 'feeling' based constructions used in accounts. All respondents talked about how they felt during their experiences but for six respondents their emotional responses (e.g. feelings of sadness, frustration or anger) were clearly more salient in their constructions compared to what happened or what they did. In relation to constructions of illness, substance use or treatment experiences it was evident that for this handful of respondents the emotional aspects of their experiences were key.

QS15: Lines 87-89 (Male, Black African)

Int: And did you - what happened when you were at [Name of Psychiatric Hospital]? Do you remember?

Resp: I just felt very, very angry and fed up with the world, and having a lot of fights with people and they had to restrain me all the time, because I was yelling at them – I wasn't used to a place like that.

I was probably the youngest person in there. I was scared and frightened so all I was doing by defending myself was fighting.

This was evident particularly when respondents were talking about their mental illness type symptoms, a notion we will explore in more detail in section 9.4.4.

### **9.3.3 How**

Part of the respondents' accounts were related to their desire to present their account within what they consider to be acceptable social models of causation of their experiences and events. Lay models of causation of mental illness experiences and substance use were one of the most prominent features of the all of the respondents' accounts. I will discuss themes on causation in the following sections but it is useful here to highlight 'how' the respondents created their models of causation.

Intellectualisation was the strongest way in which respondents explained the things they had experienced. Intellectualisation comprised several types of responses and can be categorised in four different ways; excuses; justifications; apportioning responsibility; and association. This mechanism as mentioned above can be seen as linked to social desirability (Holden, 2001)<sup>5</sup> and is similar in nature to Scott and Lyman's (1968) account classifications of either 'excuses' or 'justifications'. Scott and Lyman (1968), who have defined an account as "a linguistic device employed whenever an action is subjected to linguistic inquiry", explained that excuses and justifications arise when the possibility that an individual has acted in some 'untoward' manner is raised.

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<sup>5</sup> Social desirability is the tendency for a person to present themselves in a favourable or socially acceptable way



Excuses and justifications are defined in similar terms to those of Scott and Lynman but form only part of a larger account mechanism; Intellectualisation. Although behaviours when unwell or having mental health experiences and drug taking may have negative implications for the respondents (for example the police being called) no moral judgement is made.

Scott and Lynman (1968) believe accounts represent attempts to refute challenges either by denying responsibility (excuses; I did it and it was wrong but it wasn't my fault) or by arguing that the behaviour in question was understandable, given the situation (justifications; I did it but it wasn't wrong). These two themes were used in most accounts when respondents were describing the events leading up to a hospitalisation. They were also used when respondents were describing criminal behaviour (n=4) or when talking about not taking medication (n=2). The following are examples of excuses (QS5, highlighted in red) and justifications (QS8, highlighted in blue).

QS5: Lines 455-459 (Male, Black African)

Int: Ok and between say like 95 and 99 did you spend time with friends either from school or around your area?

Resp: We were just were just they were just leading me astray really you know doing all bad stuff.

Int: What type of bad stuff?

Resp: I don't want to say this because.

Int: Ok.

Resp: But it was all kind of bad stuff you know that I like doing trouble get into trouble you know getting into fight but I wasn't in the fights because there was one time I saw my friends get into a fight they wanted to bully somebody and instead I saw them beating up the person and they wanted me to join in but somehow I kicked the boy once and I

realised it wasn't right so then I stop and I told my friends I said no it's not worth it let let's leave him you know and but as well as I've got into trouble where it was always me getting beaten.

QS8: Lines 466-469 (Male, White)

Int: What about after that? Have you had another...

Resp: I've been stopped for being drunk and disorderly and they found a so-called offensive weapon in my pocket, a butterfly knife. Which I maintain was a defensive weapon, not that I would have ever used it, because it wasn't a very good one anyway. But anyway, that was the way it was and I was done for an offensive weapon and I was fined £250. And that was a long time ago, so that was a lot of money.

Int: Was there a particular reason why you were carrying it?

Resp: I owned it, and it wasn't illegal to own butterfly knives in those days, and I was carrying it for defensive purposes. If anyone wanted to have a go at me for whatever reason, that I'd have something to fend them off with basically.

The frequency that these two mechanisms were used can be related to several factors including the respondent's overall level of comfort with the interviewer. In one interview (QS8) the respondent who was a White male, used justifications as the backbone of his account giving, this mechanism arguable helped to frame what may be considered (in psychiatric terms) delusional and disorganised experiences.

Another aspect of intellectualisation was associations. During analysis data for this category included instances where respondents had used characters or plots in films as either a metaphor for their experiences or as a simile or comparison to their experiences. This could be either as part of their narrative or description of the experience or as a clarifying remark to the researcher. Five respondents in particular drew

comparisons between their experiences and films/TV programmes. Films were used as a way of helping the researcher understand what they were experiencing, what the experience meant to them, how they understand it themselves, and how they explained it to others. Interestingly two respondents picked the same film; the zeitgeist. When we look at the characteristics of these respondents we see that all five of these respondents are British born but from different ethnic groups.

QS16: Line 402 (Female, Black Caribbean)

Resp: If anyone would have told me they seen things before I would've said they're mad and that's impossible. How can you see something that's really not there? But it does happen. That's why I'm watching Eastenders at the moment. I'm watching Stacey and I feel really sorry for her. And I said I just...and everyone goes "Why do you, it's not real. Why do you feel so sorry?" and I said "Well that's how I used to feel".

This is arguably a form of normalising experiences and while psychiatric frameworks may be used as a way of making sense of experiences by aligning them with that of an ill person rather than the deviant person, association is similarly a way whereby many of the respondents in this study made sense of their experiences and behaviours. It also illustrates that although people who have mental health problems may not understand their illness in psychiatric terms (for example having insight) they still attempt to make sense of their experiences nonetheless.

The last aspect of intellectualisation was apportioning responsibility for the experiences. We discuss what respondents felt were the causes of their experience in detail in section 9.4.2. Apportioning responsibility formed part of respondents models of causation. The majority of respondents gave constructions of what part they felt they had played in their experiences. Whether they conceptualised themselves as mentally ill or not all respondents gave constructions of them having little responsibility for their symptoms or behaviours when they were 'unwell'.

When drug use was given as the cause of experiences excuses and justifications were used to explain substance use and again no respondents conceptualised themselves as having caused their experiences by virtue of taking the substance that led to the experiences. The following extract is an example of a respondent apportioning the responsibility of being violent before and on admission to hospital as being related to life stresses.

QS15 Lines 109-111 (Male, Black African)

Int: What did you think was causing you to be angry and –

Resp: I just felt – I just went through a rough time, was a bit fed up, lost my temper because when I do lose my temper, I got a temper.

And that's all I thought of it. And they classed me as a – what do you call it – a schizophrenic and all that. I was labelled and that, and I didn't like all of that.

Two of the nineteen respondents gave clear constructions of other peoples actions being the direct cause of their experiences

QS8 Line 78 (Male, White)

Resp: My mum told lies in front of the psychiatrists and I used to think to myself "I'm sure part of the reason why I'm here is because of the lies my mum is telling him." But obviously I was exhibiting, but that's what I'm saying, is that the way people were treating me, was making me feel ill.

What the accounts in this study show is that similar to finding of Martinez (2010) patients with severe mental illness are more likely to have a greater need to displace blame onto an external factor.

## **9.4 'I DON'T THINK I WAS PSYCHOLOGICALLY ILL. I STILL MAINTAIN THAT I WAS EMOTIONALLY ILL': CONSTRUCTIONS OF 'EXPERIENCES'**

This sub-section is the first of four sections that summarise the themes that were uncovered in the respondents' accounts. They can be considered the 'what they are saying' part of how respondents constructed their experiences of psychosis, substance use and treatment services.

### **9.4.1 Describing experiences**

A good starting point for uncovering the different constructions respondents gave of their illness experiences is to first look at how the respondents described their experiences. All respondents over the course of the interviews gave indications or signs as to how they saw mental illness either in themselves or in others. Respondents were asked what their perception of mental illness or psychiatric hospitals had been before they came in to contact with mental health services. Many respondents gave descriptions of what they thought mental illness was and ten respondents gave clear description of how they see or saw the mentally ill. Respondents were also asked for terms they used to describe these experiences and all 19 respondents gave at least one term or description of what they felt they had experienced. The terms used for their experiences can be related to how they model or frame the causes of mental illness.

#### **9.4.1.1 Terms and signs**

Table 37 shows a list of the most commonly-used terms employed by respondents to describe their experiences. Each respondent was asked how they would categorise their experiences or why they thought they

had experienced the things they had and some were asked whether they felt their experiences constituted a mental illness. As has been found in other studies (Kinderman et al., 2006), the terms that respondents used were sometimes ones adopted by the respondent themselves and sometimes ones applied by other people. The terms that respondents adopted themselves are summarised below.

**Table 37: Terms for experiences used in accounts**

	<i>n</i>	%
<b>Terms (n=19)</b>		
Psychiatric (n=3)		
Psychosis	3	15.8
Lay (n=15)		
Breakdown	5	26.3
High	3	15.8
Bonkers	2	10.5
Funny	2	10.5
Low	2	10.5
Vexed	2	10.5
Mad	5	26.3
Crazy	7	36.8
Combined (n=17)		
Paranoia/paranoid	12	63.1
Paranoid schizophrenia	2	10.5
Depressed	12	63.1
Ill	12	63.1
Mental illness	3	15.8

The terms used can be categorised into three distinct groups: Psychiatric; Lay; and Combined. Respondents on the whole tended to use a mixture of these types of terms to describe their experiences at different times within their accounts. Only three respondents used the word psychosis and all of them were from a White ethnic background.

All but one respondent used more than one type of term. Respondents could however for the most part be grouped as mainly subscribing to lay terminology or mainly subscribing to combined terminology. For a few this division could not be made as they used a mixture of psychiatric, lay and combined terms (n=6).

**Table 38: Type of terminology used by perception of experiences**

	I have a mental illness (n = 7)		I do not have a mental illness (n = 6)		Undefined (n = 6)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
<b>Terms (n=19)</b>						
Lay	1	14.3	2	33.3	3	50
Combined	5	71.4	1	16.7	1	16.7
Mixed	1	14.3	3	50	2	33.3

Table 38 shows that the majority of respondents that felt their experiences equated to a mental illness used the combined terms to describe their experiences.

Only three respondents used the term 'mental illness' and interestingly two of those respondents gave an overall construction of not having had a mental illness. This illustrates how constructions within accounts can be contradictory or how people with a 'mental illness' can see certain symptoms as being indicative of mental illness but may also believe that they do not meet a criteria for having a mental illness.

Many of the respondents talked about their experiences in terms of individual symptoms, paranoia being the most common. The term paranoia was the most complex because it drew on both constructions of mental health experiences as well as drug use experiences. Table 37 shows the number of respondents that referred to their mental health experiences as paranoia (either directly or indirectly through drug use). Many of them also used this term to describe the effect cannabis or specific types of cannabis had on them separate from mental health experiences. I discuss the relationship between paranoia, mental health and cannabis use further in section 9.6.1.

The most commonly used terms (paranoia/paranoid, n=12; depression/depressed, n=12; and ill/illness, n=12) were those that can be found in both psychiatric and lay language used to describe mental illness. These terms would have originated in psychiatric discourse, but with increasing public awareness of mental illness they have found their way into lay descriptions. The terms that can be found in both domains have been labelled combined because even though they originated in psychiatric language they have taken on a slightly different form because of lay understandings of them.

It should be noted that respondents were using terms that describe a level of 'unwellness' without directly subscribing to the psychiatric framework of mental illness. All three of these terms enable



this to some degree and detailed constructions around these terms were prominent in nearly all accounts as we will see in the following sections.

In addition, two respondents used terms in personal and an idiosyncratic way as seen in a study by Kinderman et al. (2006). Respondents slightly changed the meaning of psychiatric terms to encompass their own understandings of mental illness or experiences.

QS10, Lines 257-258 (Female, White)

Int: Can I ask you when you were in hospital did anybody talk to you about what's called like a diagnosis of why you were there? The reason why you were there – your illness?

Resp: I can't remember. I think so. They said that it could be depression. It would be psychological depression or something like that.

QS5 Lines 1130-1131

Int: Yeah have you spoken to anybody about what, a diagnose if you have a diagnosis or something. When you've been in hospital a couple of times and with a community mental health team for a while has anybody ever talked to you about a mental illness or if you have a diagnosis.

Resp: Yeah the doctor told me that I've been diagnosed with schizophrenic epilepsy or so yeah.

The largest proportion of terms used were made up of a mixture of lay and combined terms. As we can see from Table 38 these were used regardless of how the respondents defined themselves in terms of having a mental illness. This mix of terminology can further be explained by the fact that a number of respondents subscribed to psychiatric or combined frameworks of mental illness in a general sense but used lay or colloquial terms to describe their experiences or illness in a comical or self-deprecating way (n=4). The terms 'mad' or 'crazy' for example tend to be traditionally aligned with negative associations of mental illness. Even when a respondent used psychiatric or combined terms to describe their illness, they sometimes used these negative lay terms in a comical

way to describe the bizarre or deviant behaviour they had been exhibiting.

Interestingly, the respondents who used lay terms in this way tended to have manic presentations according to both their Aesop study psychiatric diagnoses as well as their own self-diagnosis (n=3).

QS17 Lines 134-138 (Female, Black Caribbean)

Resp: ...But when I'm ill, I just, don't know. It's crazy, the way I think when I'm ill.

Int: What other things happened when you were ill?

Resp: Just crazy thing like, I don't know like when, what was it? I'm just trying to think. About four years ago, I snuck into.. where was it? I don't know how I did it but I did it. I snuck into 'This Morning.'

Int: Did you? (Laughter)

Thirteen respondents needed to be prompted to give precise terms to describe their experiences. These respondents when asked initial questions about what had been happening around the time of their first hospitalisation responded with descriptions of feelings or thoughts or behaviour rather than a concrete term or concept as this example illustrates.

QS12 Lines 141-142 (Male, Black Caribbean)

Int: Okay. And so you said the doctor had asked you what had brought you into hospital and what did you think had brought you into hospital?

Resp: I just started to think about my mum again and it just went straight to my head, I couldn't cope. So I started to collapse and said "That's it, I want to die." I just had a fixation on trying to kill myself. I couldn't do it, everything I tried I failed at. So I just had to give up on that notion, nothing was working.

When we look at typologies in the data we can see that the majority of White respondents tended to use predominantly psychiatric terminology. In contrast, the Black Caribbean respondents tended to use predominantly lay or colloquial terminology. This gives us insight into how the three ethnicities may frame their understanding of mental illness, its causes and possibly the relevant treatments available to them as modelled by Kleinman (1980).

#### 9.4.1.2 What are people with mental health like?

Part of constructions of mental illness came in the form of describing other people's illness and experiences. Constructions of 'the mentally ill' were found throughout most accounts. The constructions came in prompted and unprompted form (mostly unprompted). Ten respondents gave clear descriptions of what they thought the mentally ill were like. Lay terms with negative connotations tended to be used to describe people with psychiatric problems. Table 39 gives an overview of the terms, behaviours and physical attributes that the respondents felt were associated with people with mental illness.

**Table 39: Descriptions of people with mental illness**

	prompted		unprompted	
	<i>N</i>	%	<i>n</i>	%
<b>Mental illness (n=10)</b>				
Term (n=4)				
Crazy	2	20.0	0	-
Lunatic	0	-	1	10.0
Nutter	1	10.0	0	-
Mad	0	-	1	10.0
Behaviour (n=7)				
People talking to themselves	2	20.0	2	20.0
Exploding	0	-	1	10.0
Keeping self to self	0	-	1	10.0
Chaotic/unpredictable	1	10.0	1	10.0
Doing bad things	0	-	1	10.0
Physical appearance (n=3)				
Looking dishevelled	1	10.0	1	10.0
Cannot always tell physically	0	-	2	20.0

QS10 Lines 374-375 (Female, White)

Int: ...I wanted to also ask you what you think mental illness is? Like what in your mind, what does it mean?

Resp: Mental illness to me is someone. You know like sometimes you would be walking down the street and you get that nutter, which is absolutely off his head. Talking to himself. All that. I think that is mental illness. I think people like that being locked up. Like this whole thing of like when I came to [Mental Hospital] I thought it was like a Victorian Asylum. That's what I think. But it's not like that but you know...

Respondents often used stereotypical constructions of the mentally ill even if they had been hospitalised themselves. Part of the respondents' constructions of what they thought mentally ill people were like related to whether they perceived themselves as the same or different from people with mental illness.

**Table 40: Relationship between family history and perception of self**

	Family History (n=6)		No Family History (n=13)	
	<i>n</i>	%	<i>N</i>	%
<b>Perception of self (n=19)</b>				
I am different from other patients	5	83.3	4	30.8
I am the same as other patients	0	-	2	15.4
no opinion expressed	0	-	3	23.1
undefined	1	16.7	4	30.8

Table 40 shows that 6 of the 19 respondents had family members who had a mental illness. Most respondents with a family history of mental illness saw themselves as different from other patients that they encountered. Nearly all of those respondents believed that their illness was qualitatively different from their relatives. Moreover, their own illness was described as less severe (despite the added difficulties of

substance use disorders) as is exemplified in the second half of respondent QS14's construction of 'the mentally ill'.

QS14 Lines 359-360 (Female, Black Caribbean)

Int: Do you know if your Mum had – or your Step-Dad had - that kind of perception about your illness because of what your brothers had been through?

Resp: No. Because mine was completely different. My brothers used to hear voices and hallucinate and shit like that. Mine was – my attitude would just get different. Higher. My personality would change. My mum didn't have a clue what was going on with me. She just thought that I was angry and vexed or....I think it really does stem back from when my Dad – my Dad got murdered in Jamaica. And from that my whole personality changed. I got depressed and low. I think it just stems back from that – because she just used to put it down to my Dad.

#### **9.4.2 Causation and explanation**

According to Pill and Stott (1982) broadly speaking, aetiology or causation of illness can be divided into two main groups, those which place the cause within themselves or the individual and those which place it outside themselves or the individual. Where respondents located the origins of their experiences or the aetiology of their 'disease' is roughly related to the account mechanism apportioning responsibility.

As discussed in Chapter 4, causation forms part of explanatory models of illness which encompass a person's beliefs about the nature of their problems, its severity, prognosis and treatment preferences (Kleinman, 1980). The theme around causes of the respondents' experiences can also be seen, if not directly then at least indirectly, as part of the justification or excuse process used in account giving. Every respondent had constructed a model of causation with differing emphases based on the level of responsibility (apportioning responsibility) they had

for their experiences. These models were of differing levels of coherence and consistency.

Accounts of causation and explanation fell into three broad categories; Psycho-social; Biological and Spiritual. This broadly mirrors the explanatory models uncovered by McCabe and Priebe (2004) in a study of patients with schizophrenia (Social, Biological, Supernatural and Non-specific). In addition the majority of respondents saw multiple reasons or triggers for their experiences and they did not necessarily subscribe to one aetiological framework. Table 41 shows the specific causes elicited in accounts under each of the frameworks

**Table 41: Constructions of causes of experiences**

	prompted		unprompted	
	<i>N</i>	%	<i>n</i>	%
<b>Causes (n=19)</b>				
Psycho-social (n=15)				
Stress/Life event	1	5.3	12	63.1
Bereavement	0	-	7	36.8
Relationship breakdown	0	-	9	47.4
Other person being deceptive	1	5.3	1	5.3
Personality	1	5.3	5	26.3
Biological (n=18)				
Genetics	0	-	2	10.5
Allergic reaction	0	-	2	10.5
Drug use	2	10.5	11	57.8
Not taking medication	3	15.8	2	10.9
Spiritual (n=2)	1	5.3	1	5.3

Causes were often elicited at the very beginning of interviews and were unprompted. Respondents often qualified or added to their model of causation when specific questioning around causes was asked later during the interview

Causation and explanation were elicited in accounts in two ways; as part of the construction of the respondents' first episode of illness and as part of the construction of subsequent episodes of illness. 'Episodes of illness' is part of psychiatric schema and it was difficult to unpack what was considered an 'episode' in the respondent's accounts. Often what

was described was a worsening of symptoms. Moreover it became apparent during analysis that many respondents described subsequent experiences that were similar to yet distinct from the experiences that brought them into contact with mental health services in the first place. However these were sometimes constructed in a different way.

Eight respondents only had one episode of illness and 11 respondents had more than one episode. However 12 respondents spoke of ways of managing recurring symptoms. In the majority of these accounts drug use was the reason for 'relapse' or worsening of symptoms (n=4) as was not taking medication (n=5).

Psychosocial causes (which were characterised by stress and life events) and biological causes were the most common themes in accounts. Stress, or life events, warrants attention and so is discussed in the next section along with substance use.

Personality was the second category under psychosocial causes. Six of the respondents described their personality as being related to reasons for their experiences. This may have been a pre-existing personality trait that made them susceptible to mental illness or that would exacerbate symptoms (such as being someone who ruminates or being an aggressive person).

Two respondents normalised manic or aggressive behaviour as being part of a normal response to stressors (see example below). In three accounts the respondents' personality made them susceptible to the effects of drugs (which in turn led to mental illness). In all accounts that described the relationship between personality and their experience, personality traits were not described as a direct cause; illness experiences were a combination of personality traits and other things (e.g. a personality of thinking too much + skunk = paranoid experiences).

QS1 Lines 103-105 (Male, Black Caribbean)

Resp: I think that's part of why I was paranoid and why I needed to get a lot of shit out of my system because my brain, not that I find it hard to go to sleep but sometimes if something's not bothering me but if I'm thinking about something I think quite intently on it,

Int: yeah

Res: I'm quite a what's the word thorough, I like to open things a little bit and combine that with skunk it makes it worse, some people it just mongs them out where they can't do anything, other people it just kept me awake, I can remember weeks before going into hospital sleeping maybe one or two hours a night proper narcoleptic

Drug use (not including alcohol) and not taking medication were two of the causes related only to experiences that happened subsequent to their first experience of psychosis or episode. By the nature of the respondents' illness pathways, the theme 'not taking medication' was reserved only for explaining episodes of illness or mental health experiences after their initial episode. Pescosolido (Pescosolido & Boyer, 1999; Pescosolido, 1991) constructed the Network Episode Model based on the work of Clausen & Yarrow, (1955), and proposed that models of belief would be influenced by the 'illness career' of the sufferer. This was apparent in accounts in this study and gives some indication that many of the initial aetiological frameworks are seen as (retrospectively) fluid and renegotiable.

Personality as a cause is the only aetiology that could be considered fixed. However additional theories of causation could be retrospectively added as participants had more illness episodes or experiences.

The final category, spiritual causes was endorsed by two respondents from Black ethnic groups (Black Caribbean and Black African). As we discussed in Chapter 4 Caribbean's can hold traditional beliefs that attribute madness to the intrusion of spirits, 'obeah' (black magic) (Littlewood, 1988; Laguerre, 1987; Fisher, 1985; Morgan et al.,



2004) or 'worries' caused by external pressures. This was evident in one female Black British born Caribbean respondent. The other respondent who subscribed to a spiritual framework was a Black British African male and he gave slightly less clear constructions of the causes of his experiences, but saw them as being outside of his control and as a possible punishment from God for things he had done.

QS5 Lines 544-551 (Male, Black African)

Int: And so what happened after that?

Resp: I brush it again and again until, until I start think I was feeling better but then I was getting paranoid say it would happen again I weren't able to breathe and I pray that it won't happen again and somehow yeah and it happen for that it stopped for that day and then the next day it happen.

Int: It happened again?

Resp: Yes you know and you know it was it was if yeah I felt as if there was some kind of like evil spirits against me and yeah and, and maybe it was because of the friends and the, the way of life I was living that's all led me to this.

Int: Ok.

Resp: Yeah.

Int: So that it was like a kind of I don't know how to put it like a punishment is that what you mean?

Resp: I don't know maybe yeah it could have been a punishment you know from god or maybe, maybe it was just a curse.

**Table 42: Frameworks of causation by AESOP ethnicity**

	White (All)		Black Caribbean		Black African		Other	
	(n=7)		(n=7)		(n=3)		(n=2)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
<b>Causes</b>								
Psycho-social	1	14.3	3	42.9	0	-	0	-
Biological	1	14.3	1	14.3	0	-	1	50
Spiritual	0	-	1	14.3	1	33.3	0	-
Combination	5	71.4	2	28.6	2	66.7	1	50

Table 42 shows the primary framework of causation employed in each respondent's account by ethnic group. The majority of respondents used a mixed framework (n=10); many respondents had different frameworks for their initial episode and subsequent episodes. Black Caribbean respondents had emotional or biological frameworks, whereas White respondents tended to have combined frameworks.

There is a lot of literature around mental illness and racism in psychiatry (Bhui, 1999; Patel & Heginbotham, 2007). Interestingly none of the respondents gave institutional racism as a cause of their experiences or although one respondent gave constructions of institutional racism in the criminal justice system (this related to the causation of his family member's illness rather than his own).

#### **9.4.2.1 Stress and life events**

Stress was one of the most prominent causes elicited in accounts and was constructed from mostly unprompted responses. Respondents constructed stress as a cause of their experiences in two ways: 1) as a cause in its own right; and 2) as a way the effect of negative psycho-social (Life events) or spiritual experiences were manifested, which in turn caused their mental health experiences.

Stress was conceptualised in several ways. In some accounts, the respondent assumed it was an agreed concept between them and the researcher and they did not give any specific examples or definitions of what was stressful for them. In other accounts, examples were clearly given. As we can see from Table 41, 13 respondents believed stress to be a cause of their experiences. For all of these respondents, stress was considered a cause in conjunction with other factors. The majority of respondents gave major life events as the cause of their stress, such as relationship problems or breakdown (n=9) or bereavement (n=7),

however everyday stresses were also considered causes or triggers and in 3 respondents the stress of not sleeping were mentioned.

Stress as a cause in its own right was conceptualised as 'stressing out', worry or anxiety. This type of stress was elicited in four accounts and constructions were often unclear which is illustrated in the example below.

QS14 , lines 466-467 (Female, Black Caribbean)

Int: How would you kind of summarise it? Would you say it was a mental health issue, would you say it was something else...?

Resp: No, I got stressed out. I didn't know how to cope with it. I wasn't used to stress and everything on top of me. And that was my outlet. Just getting mad, angry, going out, staying out. That was it. I don't think I have got a mental illness, or I am mad or anything. I just get stressed sometimes. And my way of dealing with stress is different to people – other people. Simple.

This type of stress was mediated by two factors: 1) the ability to cope with stress and; 2) the individual's personality (for a minority of respondents). The focus in some accounts, on the ability to cope (as illustrated above) was typically seen in the latter parts of a number of accounts whereby the respondents talked about learning to cope as a strategy for managing symptoms or triggers/causes of their experiences.

#### **9.4.2.2 Models of multiple causes and mediators**

Ten of the respondents believed there to be more than one cause of their experiences. In these accounts multiple causes were seen as additive.

QS17 Lines 377-378 (Female, Black Caribbean)

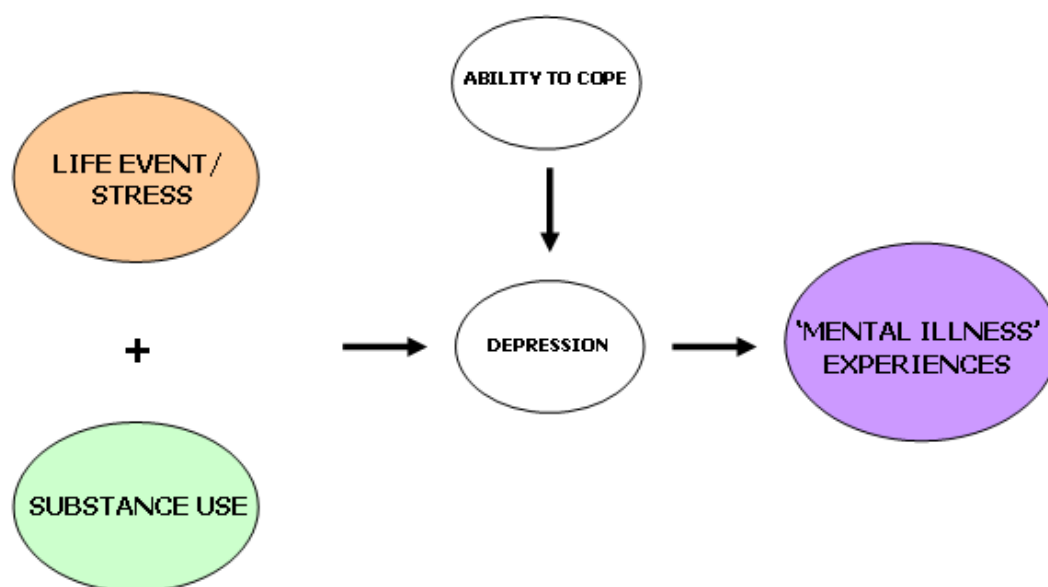
Int: Do you ever feel that any of the drugs is related, or has contributed, or has made better, any of the experiences you've had?

Resp: Yeah I think probably it has contributed. I'm probably in denial saying weed don't do anything. But I think, with the mixture of charlie and coke, I mean, charlie which is coke, weed, and the madness at [Person's house where she believes a spiritual ritual was performed], it all infused together. So it did affect me.

The most common combinations of aetiological frameworks were life events or stress in addition to drug use. Figure 17 shows a typical model of causation. In this model a life event or stressor combined with substance use leads to low mood or depression. The experience of depression is mediated by their ability to cope with the stressor. This in turn leads onto other experiences (psychotic) that put them into contact with services. Depression is seen as the beginning of their experiences and in many respondents their experiences are categorised as solely depression, a notion I will discuss in section 9.4.3.

As I discussed in the previous section, the respondents that had more than one episode of illness often changed their causation model to accommodate either their continuation or discontinuation of cannabis use or the effects of not taking their medication. Stressors were still seen as triggers for illness episodes or recurring symptoms, however in five respondents medication non-compliance played its role.

**Figure 17: QS11 (Male, Black African) Model of causation for initial episode**



**Figure 18: Typical model of causation for subsequent episodes of illness/experiences**

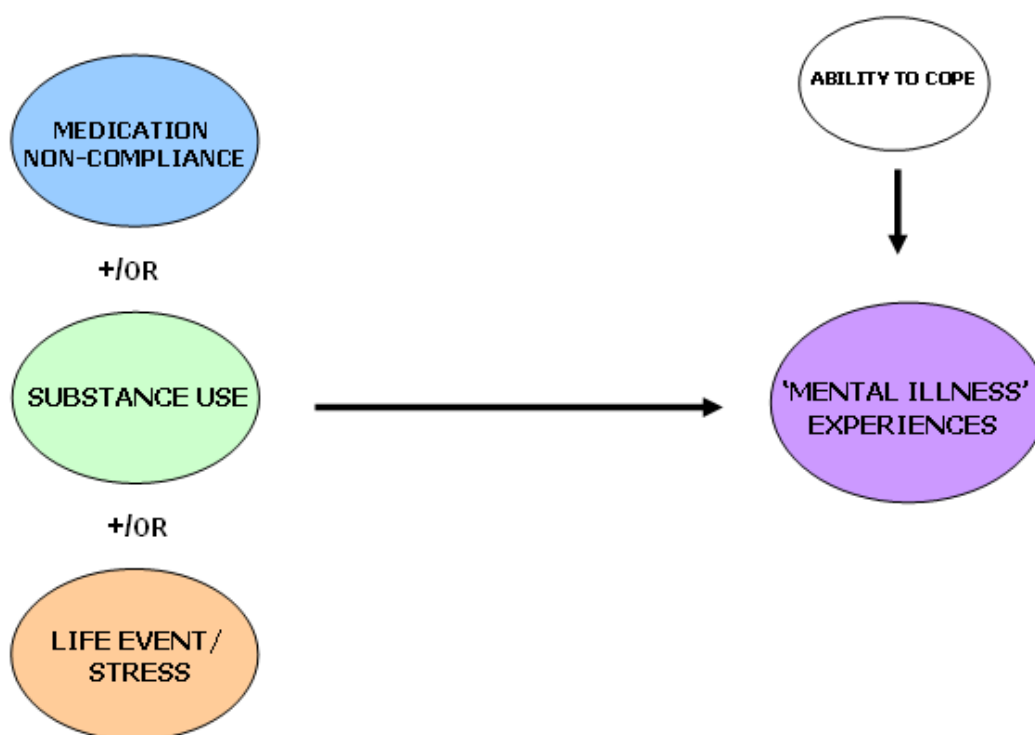


Figure 18 shows the most common (n=8) model of causation for subsequent episodes of illness or relapses. This second model is based on a construction of illness experiences, that for some respondents, had changed the respondent in some permanent way, such that it may require abstinence or reduction of substance use (often cannabis) and/or medication as is illustrated in the following account.

QS18 Lines 141-142 (Male, Other)

Int: So did you put down those experiences to smoking the cannabis? Or did you think there was another reason?

Resp: My reasoning was that there was some kind of gate that stops normal brain, I guess neurology to perceive the world in that kind of way. Then LSD kind of opened those gates towards that perception if you like. (Laughter) And because that door had been swung open it became accessible with lesser potent drugs like cannabis. And because I was smoking quite heavily I started feeling that kind of effect or perception; however you might want to put it.

In this model, respondents give different weight to on-going substance use, life stressors and medication non-compliance. These weights are dependent on several factors including how they construct the aetiology of their illness experiences (their first model of illness causation), whether they believe they have a mental illness or not, whether they want to continue using substances (or a substance) or not, whether they consider there to be a relationship between substance use and mental illness and whether they believe psychotropic medication is benefiting them.

#### **9.4.3 Depression is not a mental illness**

‘I wouldn’t say it was a mental illness. But it was more depression’.

QS10 Line 272 (Female, White)

While 12 of the respondents used the term depression to describe some or all of their illness experiences, four of the respondents felt that depression solely explained their experiences. In these cases their psychotic type experiences were constructed as the additive combination of depression and drug use (or in the case of one of the respondents an allergic reaction to prescription drugs) rather than a psychotic illness.

QS15 Lines 242-250 (Male, Black African)

Int: And you said at the time, that the first time you were in hospital, you didn't feel that – they were saying you had a mental illness, and you didn't feel you did. What do you think now?

Resp: I still think I didn't have a mental illness, I was just depressed. I didn't think I was mentally ill, something like I hurt someone or do something to someone. I just think I had an allergic reaction with the pills [prescription drugs that family gave him], lost my temper and that was it basically.

Then they section me, and from then I been under the mental health treatment.

Int: Since then. Now, what you do think now? Do you think you have a mental illness now?

Resp: Kind of like, the stuff I've been through, I do need to take medication to stabilise my mind so I kind agree. Then I was young and I was confused, I didn't know what's going on.

Int: Do you have your own name for what you think you're going through or you've experienced?

Resp: I just think it's depression.

Int: You think it's depression?

Resp: Yeah.



In this extract the respondent sees that it was his aggressive behaviour caused by a reaction to the medication his family had given him that led to his sectioning. He does not see that he has a mental disturbance. Moreover he does categorise his experiences as having suffered from a depression, but this is differentiated from a 'mental illness'.

Although there were not enough respondents that conceptualised experiences in this way to look at patterns of constructions by gender or ethnicity it provides us with a first look at how drug use and psychotic experience are interwoven in the constructions of comorbid experience.

#### **9.4.4 Feelings, thoughts and behaviours: symptom experiences**

Data under the theme 'symptom experiences' included instances where respondents constructed aspects of their experiences in terms of the feelings they had (e.g. emotional feelings like 'being low' or sensations like visual or auditory hallucinations or odd sensations), the behaviours they exhibited (e.g. criminal behaviour) or the thoughts they had (e.g. paranoia). This theme builds upon the account device 'Feelings, thoughts and behaviour' by examining how the respondents felt or what they did. Descriptions under this theme relate solely to 'how' a symptom (defined explicitly or implicitly) was constructed and what symptom-like and related experiences were salient to people with comorbidity. This theme is illustrated in Figure 19.

One of the symptoms that ten of the nineteen respondents described was sleep deprivation. This experience tended to be described as the noticeable onset of problems.

QS3 Lines 420-423 (Male, White)

Int: So is that something that you identify now rather than at the time did you think at the time that maybe smoking was contributing to your experiences?

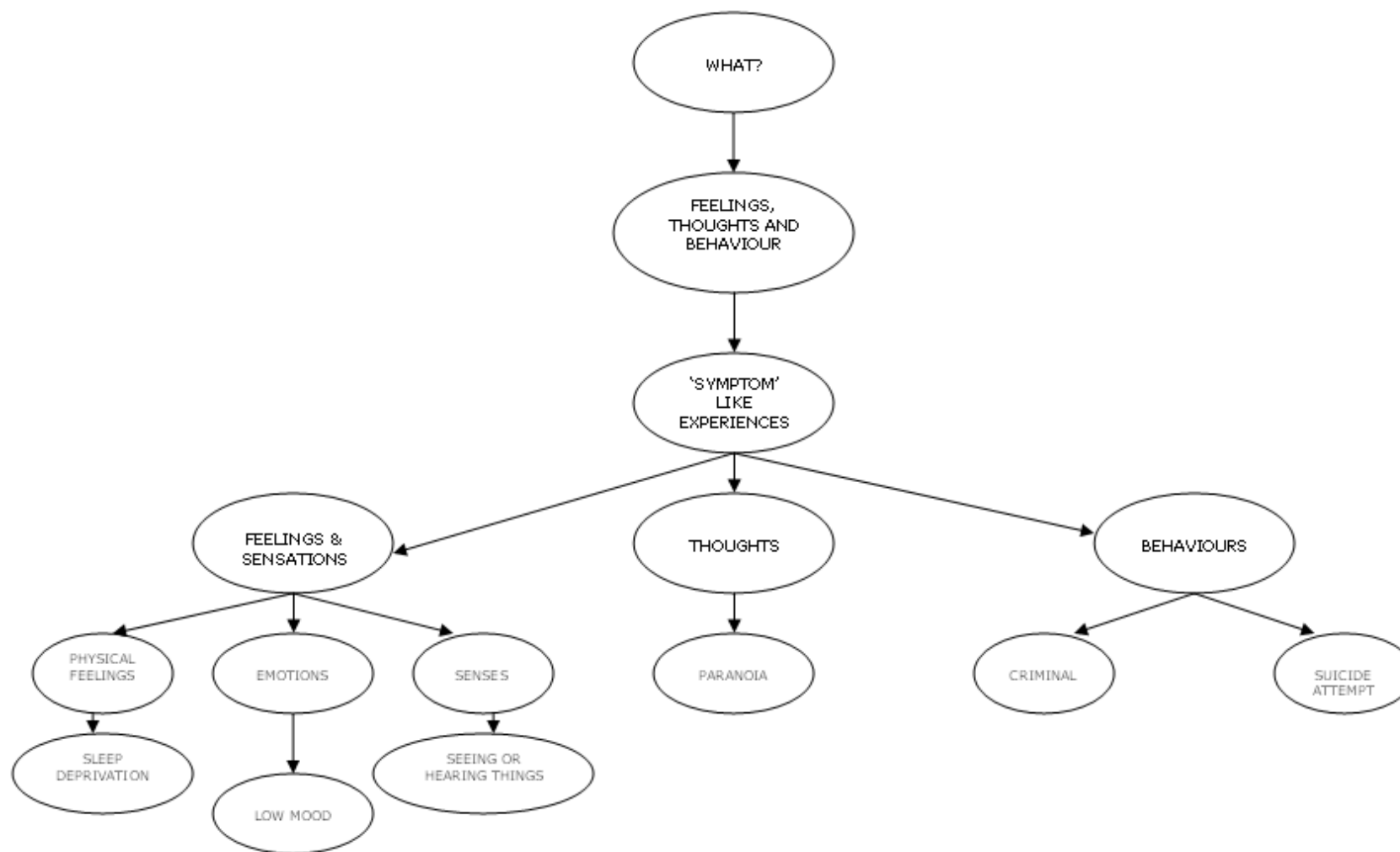
Resp: Yeah I was convinced that it was because I, I, I thought I got spiked basically.

Int: Right.

Resp: And before that a couple of days before it happened and I started to lose sleep and develop insomnia it was all it was quite a short build up but quite a big explosion.

As we saw in section 9.4.1.1 12 of the respondents used the term 'depressed' to describe the whole or part of their mental illness experiences. Section 9.4.3 also discussed the relationship between depression and constructions of illness, however it is noteworthy to mention here that depression or low mood was also seen in a more symptom like manner (normally as a response to a life stressor and as a precursor to other experiences) in two respondents rather than a disorder in its own right.

**Figure 19:**      **Constructions of symptoms and related feelings using account device 'What'**



Five of the nineteen respondents described seeing or hearing strange things as part of their experiences. These descriptions bear similar resemblance to what would be considered hallucinations, but only two of the five respondents used that term. Two of the respondents saw these experiences as being solely related to their drug use.

Twelve of the respondents described having paranoid experiences. As we will discuss it is difficult to unpack these experiences because they can be considered a symptom of mental illness as well as drug use (specifically cannabis). Nevertheless, five respondents talked about paranoia as being separate from drug use.

QS9 Lines 212-217 (Male, White)

Int: That's good. So you've said you haven't had any experiences up until recently? You came to hospital in December, is that right?

Resp: That's right, yes.

Int: So what had been happening?

Resp: I was having paranoid thoughts and hearing voices and hallucinations again. I found it a little bit strange because that's the sort of thing I experienced when I was using drugs, but I hadn't been using anything. But I just out of the blue had these feelings come back.

Apart from paranoia, bizarre beliefs which are of delusional quality are also a characteristic of schizophrenia. Two respondents spoke about beliefs that were 'out of the ordinary' and only one of them used the term delusion to describe these experiences.

QS4 Lines 533-535 (Male, White)

Resp: I'm prescribed three five mgs tablets a day of Diazepam and that's what I keep to.

Int: That's what you take?

Resp: And I take them sporadically, I don't take them, they were given to me for delusions, is what they called it? When I thought people could read my mind looking back I know exactly what it was it was kind of flashback things of the telepathy that I felt was real at the time of taking drugs looking back it was me getting anxious which then led to the racing the endorphins in my brain an active transmission whatever you want to call it would bring hallucinations and they were horrific you know and I was prescribed Diazepam because it would tranquilise.

The last aspect of symptom like experiences was found in the description of behaviours exhibited prior to or on admission to hospital. These behaviours can be categorised into two types: criminal behaviours and suicide attempts. Criminal behaviours were described in six accounts and in two of these they were related to behaviour when the respondent believed they were 'high' (what might be termed in the psychiatric field as a manic episode) or having a manic episode. Four respondents described criminal behaviour associated with their illness:

QS13 Lines 227-235 (Male, Black Caribbean)

Int: Was that the only time you've had any contact with the criminal justice system?

Resp: No, I've got common assaults, that's it really.

Int: And when did that happen? How old were you when that happened?

Resp: I can't remember how old I was, but back in hospital, having a fight with the nurses.

Int: And they pressed charges?

Resp: Yes.

Int: How did you feel about that?

Resp: What can I say in it. I was ill wasn't I? I still don't like to hit somebody.

Others (n=2) described criminal behaviour associated with substance use.

QS11 Line 31 (Male, Black African)

Resp: The crack became everything because the issues were there and the crack was dealing with the issues. It became my friend, really. And unfortunately, when my money ran out at the bank. I wasn't working at this time because my self-esteem and everything had gone. When the money ran out of the bank, I began associating with this girl and the company that she kept. And this company wasn't very decent company. Went into shops and started nicking bottles of whiskey and things like that.

One of the difficult experiences that was elicited in accounts was that of attempting suicide. Five respondents spoke about trying to end their life and in all of these cases those feelings were precipitated by a difficult life event or stressor and formed a significant aspect of their whole mental illness experience.

## **9.5 CONSTRUCTIONS OF DRUG AND ALCOHOL USE**

Constructions of drug and alcohol use fell into three main areas: reasons for the initiation of drug or alcohol use; substance use after their initial episode of illness or mental health experiences (whether they continued using or not); and construction of what constituted a problem with substances (i.e. an addiction). Each of these themes is discussed in detail in this section and then the relationship between substance use and mental health experiences is discussed in the next section.

### 9.5.1 The type of substances used

During the course of the interview all respondents were asked questions about their substance use. Many gave unprompted descriptions of their drug use as a cause of their experiences (see section 9.4.2). All respondents described having used cannabis in their lifetime. All respondents had also used alcohol at some point during their lifetime with 18 of the 19 reporting regular use (n=18). However, only six respondents thought that their alcohol use had ever become problematic. In addition to cannabis and alcohol use, there were a number of other drugs that respondents described using.

**Table 43: Types of Substances used in the lifetime**

	<i>n</i>	%
<b>Types of substances used</b>		
Tried but not used regularly		
Coke	5	26.3
Crack	2	10.5
Heroin	2	10.5
Ecstasy	4	21.1
Alcohol	1	5.3
Used regularly and/or considered problematic		
Coke	1	5.3
Crack	2	10.5
Heroin	1	5.3
Ecstasy	3	15.8
Speed / Amphetamines	5	26.3
LSD / Hallucinogens	4	21.1
Cannabis	19	100
Alcohol	18	94.7

Respondents were asked what their perception of their substance use was and whether they felt they had a problem with the substances they used. As we can see from Table 43, only five of the respondents had an AESOP diagnosis of both drug and alcohol use disorder (DUD and AUD). Respondents who had been given a diagnosis of comorbid DUD only in the AESOP study elicited mixed perceptions as to whether they felt they had a problem with drug use. However all of the respondents that had an additional diagnosis of an AUD felt they had a problem with substance use.

**Table 44: Perception of substance use by comorbid diagnosis**

	I do have a problem with substances (n=11)		I do not have a problem with substances (n=4)		Undefined (n=4)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
AESOP diagnosis of comorbid DUD	6	54.5	4	100.0	4	100.0
AESOP diagnosis of comorbid DUD and AUD	5	45.5	0	-	0	-



It is not surprising that there was a disagreement in the perception of problematic substance use between mental health practitioners/researchers and the respondents themselves. This theme is strongly elicited using the account mechanisms excuses and justifications. Many of the respondents used social setting and normal behaviour for their peer group as either a justification for drug use while others excused their drug use because they considered it a coping mechanism.

### **9.5.2 Initiation of substance use**

One of the less prominent themes was how substance use was initiated. Because of the obvious cultural and legal differences in the use of alcohol and drugs, questions around substance use and unprompted responses tended to be focused on illicit drug use. Probing questions were asked about the initiation of drug use, and only a few respondents spontaneously talked about why they started using drugs. Instead, they focused on why they take drugs in general. Nevertheless conceptualisation of the respondents first experience of drugs (and alcohol) as well as how drug taking progressed and changed over their life were elicited in all account.

Reasons of initiation of substance use can be categorised into three main areas: psycho-social reasons; physical reasons; and situational reasons. Initiation of substances was defined as initial use of an illicit drug or excessive use of a prescribed drug. Initiation of alcohol use was defined as the respondent using alcohol regularly or frequently. Only three respondents spoke about how they first used alcohol differently and all three conceptualised the initiation of their regular use as the beginning of more problematic use.

**Table 45: Constructions of reasons of initiating substance use**

	prompted		unprompted	
	<i>N</i>	%	<i>n</i>	%
<b>Reasons (n=19)</b>				
Situational	19	100	0	-
Physical	2	10.5	3	15.8
Psycho-social	7	89.5	0	-
Depression / Grief	2	10.5	0	-
Bad relationships with friends or family	4	21.1	0	-
Stress	0	-	1	5.3

Table 45 gives a summary of respondent conceptualisations of their substance use initiation. As with the theme around causes of mental health experiences, respondents often gave more than one reason. Eleven of the respondents only gave one reason for the initiation of substance use.

#### *Situational reasons*

In all of these instances, when the reason given was situational it often included the initiation of multiple substances. Respondents attributed the reason for first using the substance as being related to their immediate social situation. In those cases, the respondents did not attribute any emotional, personality, physical or economic reason to drug taking. It was considered an incidental part of growing up and socialising. Respondents reported seeing family members or friends using drugs (in particular cannabis and LSD) and they were merely 'experimenting' with that person when the opportunity was presented in social situations. . This reason for initiation was normalised for both drug and alcohol use and in keeping with the respondents immediate sub-culture.

QS4, Lines 216-229, (Male, White)

Int: So did this start in your what year were you in when this started when you started going out?

Resp: Well I mean the, the it kind of like it started I think smoking weed started at school.

Int: How old were you?

Resp: That would have been 16 17 the classic way mates got a joint do you want to try I remember the first time I smoked it, it had no effect nothing didn't puffed away nothing what's all this about.

Int: What's this?

Resp: Everyone else was giggling I'm sitting there eating it I think and like I just don't feel anything what's going on but I think that's because my mind was so ready.

Int: Yeah.

Resp: Kind of wow you know. That it didn't and then every so often you know have a drag and it was all very fun very giggly very munches very and in hindsight I can see the development almost to the, the specific nights.

Then you get involved in knowing someone who you can buy it off. Then you get involved in buying it for other people then you get involved in the classic they call it a step way drug I don't believe that but the possibility is there because you are buying it from someone that does also have that.

Int: That they'll be selling something else.

Resp: But yet again at art school everyone that I know smoked dope and not you know a minority did what we did.

Int: Yeah.

Resp: You know everyone puffed but you know 20% maybe which was little at that point. Took it the whole way.

This extract also illustrates the respondent's construction of how drug use developed. In the accounts of three respondents, this step-wise development of drug use is spoken about in a clichéd way but is also acknowledged as representative of their own experience.

### *Physical reasons*

Five respondents talked about the physical reasons they started using a substance. In all but one of these accounts, respondents who had already been using drugs and were initiating the use of another substance for the first time did so as a form of substitution. Substitution was considered to include examples where respondents had used a substance (drug or alcohol) as a way of coming off another drug (usually a drug other than cannabis) or alleviating the physical or psychological withdrawal from another drug. The following extract was typical for respondents that constructed initiation of substance use for physical reasons:

QS2, Lines 445-449, (Female, White)

Int: What about cocaine when did you first do that?

Resp: Cocaine well obviously when the heroin was going on I did both which was not the best ... but I did both I got really hooked on that and then obviously because I was treated with this anti... well I did a detox and I was given my dad used to give me one of those anti... pills every day so I couldn't feel the heroin I wouldn't touch the heroin but I needed the coke really badly and I kept on fixing and doing things like that and that went, went for a while kept on going but again with the cocaine it was different I just you know if I didn't have it I didn't have it you could stop it, it was a different thing it didn't have the same.

Int: What made you start using it more though when, when you, you said that when you were detoxing.

Resp: Well because well I had to use something pretty much was you know I deal with I definitely dealt with the physical side of the addiction but probably not with the psychological side of the addiction you know.

Int: Ok you wanted to carry on taking something?

Resp: I just wanted to yeah probably.

### *Psycho-social reasons*

Psycho-social reasons fell into three groups. The first of these reasons elicited in two accounts was depression because of life difficulties or grief following the loss of someone special. Four respondents talked about negative relationships with their family members which led them to try drugs. Stress as a reason was given in only one account. Psycho-social reasons were also interrelated to themes around coping.

Psycho-social reasons were also elicited in accounts in the form of self-medication. Respondents used substances to help them numb pain or get through the difficult time they were having as the following extract shows:

QS10, Lines 20-22 (Female, White)

Int: Okay. And what type of things were you kind of experiencing when you were taking the drugs. Like what?

Resp: At the time I was experiencing, you know, a high. I didn't really think about the problems that I had at home. I was more concerned about going out and going clubbing and going into clubs and getting the drugs really. Do you know what I mean? And just staying up.

Because when you're high on stuff like that you don't really think things that you're depressed about don't really matter. Because you're all about the moment. But the comedown is horrible. But that is the feeling I got when I did the stuff. I wasn't really concerned about... it's like you lose your problems. If you get what I mean.

As with many of the themes, there were no obvious patterns in the reasons for initiation of substance use by the characteristics of the respondents. This is important in that it seems from this small sample of respondents that regardless of your gender or ethnicity, or whether you see yourself as having a problem with substances, the reasons for your initial use are very similar.

### 9.5.3 Cessation and continuation of substance use

Questions around changes in drug use behaviours were explicitly asked during the interview. Respondents themselves did not necessarily see their drug use in terms of on-going 'changes', instead they often gave constructions of whether they were still taking drugs (which often involved normalisation through intellectualisation of their substance use) or whether they had decided to stop (where pride was often evoked during their account giving).

Respondents constructed their substance use after the initial episode of experiences that brought them into contact with services in three main ways, regardless of whether they had continued using substances, changed their use or stopped their use altogether. The three thematic constructions were: Psychological; economic/Legal; and social. These are summarised in the table below. The majority of respondents gave multiple constructions of cessation and continuation of substance use (n=17). Economic and social reasons tended to be elicited in prompted form whereas psychological reasons were elicited in prompted and unprompted form.

**Table 46: Reasons Cessation or continuation of substance use**

	prompted		unprompted	
	<i>N</i>	%	<i>n</i>	%
<b>Reasons (n=19)</b>				
Psychological (n=16)				
Addictive Personality	1	5.3	1	5.3
Choice or Willpower	7	36.8	9	47.4
Economic/legal (n=10)				
Legal implications	2	10.5	2	10.5
Work schedule	1	5.3	0	-
Money	7	36.8	2	10.5
Social (n=18)				
The music scene	1	5.3	5	26.3
Social relationships	13	86.7	4	21.1

### *Psychological reasons*

The psychological reasons for why substances were used after the initial episode of illness or mental health experience came in two forms. The majority of respondents (n=16) believed that continuing or stopping substance use came down to individual choice and/or willpower. This construction can be closely linked with themes around mastery and involvement in the treatment and recovery process discussed in the next sections. Choice was constructed as not being influenced by other internal (addictive personality) or external (legal sanctions) processes. It was also concerned with the benefits that could be gained from stopping or continuing.

In five accounts choice was constructed as having a tiredness of drug-related lifestyles; this gave respondents a boost of determination and a genuine desire to stop. Respondent QS2 talks about stopping drugs when she started her Hepatitis C treatment because she was tired of putting her family through it. For QS11, it was the effects of being in prison and how that affected his family that led him to choose to stop. For QS3, it was the possibly being ill again.

Moreover, having a 'turning point' or reaching 'rock bottom' seemed to be a concept that ran through constructions of choice. For those that continued using substances, justifications were often used in descriptions of continuation. In QS1's account, he talks about being able to recognise the different sensations of certain types of cannabis which has allowed him to continue using weed but stop using skunk.

QS1, Lines 309 (Male, Black Caribbean)

Resp: I smoked differently. When I came out for the first year I never really smoked any weed and after that when I started working again I smoked maybe one or two spliffs a week and that was usually.

Actually I did smoke skunk after I came out of hospital after about a year or so and as I smoked a joint or half a joint, you know when you can feel not familiar feelings but familiar sort of sensations that sort of make you sit and draw back on the drug and think well that didn't really agree with me, let me put that down and now if we're at a party or something and I picked up a joint that had skunk in it even if it was a joint that you couldn't really taste it after two or three drags in five or ten minutes I'd know whether or not I could smoke the joint so yes I haven't smoked any skunk now for about a month after I came out of hospital would have been 2001, since 2001 so it's since 2002

Only two respondents felt substance use was related to having certain personality traits such as an addictive personality.

QS4, Line 331, (White, Male)

Resp: ...I think and your partly a product of your environment but your partly you know the genes in you, you know its nature that nature nurture thing and I think somewhere along the line I would have got I would whatever have got completely fucked up on a substance but in my life at this time it was ecstasy and raving it could have been alcohol at a different and in a different place it could have been heroin, it could have been benzos, it could have been anything but that's what happened to me at that time.

#### *Economic and/or legal reasons*

Economic and/or legal reasons for how substances were used after respondent initial episodes were not as common as psychological or social. Nevertheless ten of the nineteen respondents spoke about how economic or legal considerations played their part. As the term suggests legal implications related to whether a respondent (n=4) felt their substance use would have implications for their legal status (i.e. whether they would get arrested to go to prison or have some other legal problem). Constructions around legal implications only related to whether a respondent should cut down substance use or stop altogether. Only one respondent talked about their job as a consideration for how they used



drugs. This was specifically in relation to them not being able to use as much because of the hours they would be working.

Nine of the nineteen respondents elicited financial reasons for how they had or would use substances. Not having enough money was frequently given as a reason for not using substances but only related to changes in use and not cessation (n=8) and being able to use substances when they wanted because of extra money obtained through benefits was spoken about in two accounts. In one account the respondent mentioned being able to make money from discontinuing drug use because of a drug treatment programme that used a form of contingency management.

### *Social reasons*

The most common explanations for how substances were used after the respondents 'first episode of psychosis' were social, with 18 of the 19 respondents using social reasons as part of their explanation. The first thematic construction under this explanation is the relationship that respondents drew between their drug use (namely party drugs such as ecstasy, LSD and cocaine) and the music scene in their local area. Enhancement of the enjoyment of music was a way of justifying drug use and formed a firm part of six of the respondents' cultural identity when they were using heavily. The relationship was seen as both positive and negative.

### QS4, Line 207, (Male, White)

Resp: Yeah but I, I remember puking up three pills and just going through the puke and taking them again, again it started off going out at a well it didn't start it started off from [Place name] where I did my foundation in art and we used to go into the city go to different clubs it was when jungle it was just starting and we used to go to a club called the paradise club in Islington and it was like a proper hardcore sort of rude boy yardi kind of place how it ever kept its licence I don't know but it was kind of like funny because our group of people we called or we became known as the clueless possey because it was really a group of white middle class upper middle class art students taking loads of drugs not really knowing what was going on.

Social relationships (with friend and family), was another reason for changes to substance use. Constructions included reaffirming positive relationships as we see in the following extract where the respondent is talking about why he drinks alcohol.

QS8 Lines 233-235 (Male, White)

Int: And is that to help?

Resp: Probably yes. It's to get away from everything really. No it's not to get away from everything at all. It's to make friends. Although I will be chatting away to the cabbies and all that, maybe I'm changing. Maybe I'm actually changing and I'm not as introverted as I used to be. I'm definitely more lonely than I used to be.

So therefore I can't afford to be on my own. So therefore I'm making more of an effort to reach out to people. But if I want to make a real friendship and I want to start talking to someone, I will have to be a little bit drunk.

Constructions also included repairing broken relationships as we see in the following extract; the respondent (who joined a drug treatment programme to become abstinent from all drugs) describes what happened to his family relationships when he was using.

QS11 Lines 173-175 (Male, Black African)

Int: No, I understand what you mean. Can I ask you, how was your relationship with your siblings when you left hospital in 97? What was it like?

Resp: I went back on the drugs so there was no relationship. That thing is an evil thing. It takes away everything. It takes away your children, it takes away your ambitions, it takes away your family, it takes away your good friends. Friends that care, friends that don't use drugs, you don't want to know them because they don't use drugs. It takes away your quality of life, it takes away everything. That's number one, it comes before everybody. Without that, if I didn't have that then the emotions are going

to come back; I want to see my kids and I'm going to cry and why can't I see my kids?

And then you think, I don't want to see my kids in this state that I'm in. I'm embarrassed, it's not how I used to be. Meeting my partner, she's going to faint. This is not the man that I married. So the shame and embarrassment makes you avoid that. But now I can say, I want to see my kids.

#### 9.5.4 Constructing addiction

A smaller but no less important theme was that of addiction. Eleven of the respondents described aspects of what they felt constituted an addiction. These mostly fell into three groups: Physical, Social and Psychological (see Table 47).

**Table 47: Constructions of addiction**

	prompted		unprompted	
	<i>n</i>	%	<i>n</i>	%
<b>Type of addiction (n=11)</b>				
Physical	1	9.1	2	18.2
Social	0	-	3	27.3
Psychological	3	27.3	6	54.5

Physical aspects of addiction related to whether respondents experienced the need for certain sensations associated with that substance (e.g., needing the buzz or relief when the buzz comes or suffering from withdrawal symptoms). Social 'addiction' however was defined not by the respondents' ability or inability to retain normal social function. These constructions included examples where the respondent felt their social and economic function (i.e. going to work every day, dressing well or socialising) had not been impaired by drug or alcohol use and consequently they did not have an addiction. Examples also included instances where respondent felt that their addiction had not been noticed because they maintained normal functioning.

QS2, Line 389, (Female, White)

Resp: Experimenting yeah absolutely, you would do anything that would come up in your hands after, because it was a new thing [talking about heroin use] a new opening in the country and, and then you know and then I got addicted to it and I needed more just to keep me going basically and but still you know I worked as a PA for seven or eight years absolutely fine nobody ever noticed family didn't notice you know I had money enough to deal with it so it was only when the money came short that things started getting.....

Psychological addiction was mentioned by 9 of the 11 respondents. Two forms of psychological addiction stood out in these constructions; coping and control. Examples within this theme were where substance use became a necessity for coping with either mental illness symptoms, life stresses or just to help cope with daily life. In the following extract, respondent QS4, who later in his account gave clear constructions of having an addictive personality, talked about how alcohol became one of those addictions.

QS4 Lines 323-325 (Male, White)

Resp: When they'd come back and I'd I mean I was using alcohol then just to numb the pain I know it's like a bit of a but to numb it to numb the paranoia. To because it was just I was living it 24 seven. I can't impose enough.

Int: So you had.

Resp: I was living in hell.

Also within this category is control. This concept was considered to be a way of determining whether or not the substance use (even with addiction) was problematic or not. Respondents defined having a problem or an addiction by whether or not they had the will power to stop using.

It should be noted that not all constructions of addiction were clear. In three accounts, a general construction of addiction was given. For some of the respondents their constructions did not fall into the categories above. Instead, frequency, amount or length of use, as well as constructions of over indulging formed part of their understanding of as addiction.

QS19 Line 141, (Male, Other)

Resp: But I did have an addiction on Speed for a while but then that's because someone gave me it in a large quantity. A very, very large quantity, yeah and I was out of it for a while. And we was just addicted on it – we were just all addicted it. And so we all got a bit smashed on the Speed for a while for I don't for a month.

What is interesting is that only one of the five female respondents did not give a construction of addiction, which might highlight gender differences in the need to make sense of or intellectualise their experiences of problematic use.

## **9.6 THE RELATIONSHIP BETWEEN SUBSTANCE USE AND EXPERIENCES**

In the previous two sections we have looked at how respondents constructed their experiences of psychosis and how they constructed their experiences of substance use. A central aim of this study is to examine the relationship between mental health experiences and substance use in this comorbid group of respondents. The first example of the relationship between psychosis experiences and substance use was found in section 9.4.2 where we saw that drug use was considered to be one of the identified causes of experiences in 13 respondents. Additionally, substance use was seen as contributing to worsening of symptoms or illness relapse in many respondents and was firmly built

into models of causation for the initial episode as well as subsequent episodes.

In this section, we look more closely at the models of causation for psychotic experiences and unpack the role that substance use plays in symptom management, treatment and recovery. Table 48 presents four main areas where respondents felt they could see how their mental health experiences overlapped with their substance experiences.

**Table 48: How substance use was related to mental health**

	prompted		unprompted	
	<i>n</i>	%	<i>n</i>	%
<b>Relationship (n=19)</b>				
Self-medication with substances	3	15.8	9	47.4
Paranoia	7	36.8	2	10.5
No relationship: non-problematic cannabis use	6	31.6	3	15.8
Health professionals highlighted negative effects	5	26.3	0	-

Nearly half of the respondent (n=9) spoke about their drug use and experiences of paranoia. Most responses were prompted. This will be discussed in more detail in the next section, but first it is useful to highlight the other three ways respondents combined constructions of substance use and their mental illness experiences.

Using substances to self-medicate was a theme that related closely to constructions of coping. Self-medication was defined as instances where respondents detailed using substances to numb the pain of depression or difficulties of psychotic phenomena and mostly arose in unprompted form. Over half of the respondents (n=12) detailed using drugs or alcohol in this way at some point since their first episode.

QS14 Lines 267-274 (Female, Black Caribbean)

Int: Did anyone talk to you about smoking weed? Any of the psychiatrists?  
Or any of the nurses?

Resp: I think so, yes. Especially when they found me smoking it in the hospital and told me I shouldn't be doing it there and encouraging other patients and this, that and the other. "It's not good for your health", and "it'll make you worse", and, yes....

Int: What did you think?

Resp: I thought it was making me better.

Int: What was it doing that you needed? What kind of a buzz did you get out of it?

Resp: I thought that it was because...when I am high I get racing thoughts as well and I think it used to calm them down, you know, so I wouldn't have to think so hard, or I could understand my thoughts, instead of them racing into one.

Int: You could slow down.

Resp: I could slow them down, yes. I didn't want to eat. I didn't want to cook or do anything. I was just very chaotic.

Five of the respondents gave prompted constructions of health professionals having highlighted the negative effects of substance use on mental health. For these respondents the relationship between substance use and their experiences was only made on the advice of health professionals and not because the respondents saw a link themselves.

The perception of cannabis use as not being problematic is an important theme to highlight as well. Seven respondents described having changed their cannabis use (decreased) since their first contact with services. Of these seven, six of them gave constructions of them having viewed their cannabis use as not being problematic at some point since their index episode. Equally, of the ten respondents that subsequently stopped using cannabis altogether, three gave constructions of them not seeing their cannabis use as problematic at some point in the last 8-12 years.

### **9.6.1 Paranoia and cannabis**

Many respondents saw a clear relationship between their paranoia and their drug use. For some respondents the paranoia was seen as an effect of drug use (mostly cannabis use) rather than a symptom of a mental illness. For example respondent QS15 in this extract sees his paranoid experiences as associated with cannabis use. He had spoken earlier in the account about the types of difficult experiences he had had (depression and irritability) but these were seen as separate from the paranoia.

QS15 Lines 124-127 (Male, Black African)

Int: Was there anything else you were experiencing apart from the depression and the irritability and anger – was there anything else? Did you ever get worried about people wanting to harm you or see things you hadn't seen before?

Resp: No. All I, them days – all it was, I just used to smoke a lot of cannabis. I think I suffered from a bit of paranoia.

Int: Do you think that was to do with the cannabis?

Resp: Yeah, I do think that was to do with the cannabis..

A typical model of illness causation was apparent in the respondents that saw drug use as a cause of their paranoia: drug use → paranoia + life events = nervous breakdown. It was not always apparent in accounts however where the drug use based paranoia ended and the mental illness paranoia began (or indeed vice versa). Furthermore as we see in the following extract from this one account, it was not always clear whether or not paranoia as a product of cannabis use was considered the same as paranoia as a product of abnormal psychological processes.



QS1 Lines 62-66 (Male, Black Caribbean)

Resp: I'd been moving around again I'd been moving around a lot and I was living away from home quite a way away from home and not that it's attributed to my problems but I was having trouble with my bird, I was having trouble with drugs, major trouble with drugs as well and it was affecting my head with paranoia and stuff like that

Int: yeah

Resp: and my Mum basically admitted me voluntarily to the Bethlem hospital and where I was so paranoid for the first, for the first week I thought that I was being set up to be sent to prison I was that paranoid

Int: yeah

Resp: and the first month after that it took at least a month for the paranoia to work itself out of my system, television talking to me, people saying things and meaning other things and me reading too much into things as well. I kind of think too much anyway

An important factor in the relationship between cannabis and paranoia in respondents' accounts was their decisions to reduce cannabis use. Ten respondents choose to stop their cannabis use after their initial episode of psychosis. In all of these accounts respondents gave paranoia or fear of paranoid experiences returning as one of the reasons for cessation.

QS18 Lines 390-397 (Male, Other)

Int: (Laughter) Okay. Can I just ask you actually about, just going back to smoking cannabis, after you - did you smoke cannabis when you were in hospital? Do you remember?

Resp: No I don't think I did.

Int: And after you left hospital did you continue to smoke as much as you had before? No. Smoked more? Smoked less?

Resp: Smoked less.

Int: Smoked less, any particular reason?

Resp: Paranoia.

Int: Okay so you linked - so you saw a link between the cannabis and the paranoia?

Resp: I did see a link; yeah there was definitely a link between smoking cannabis and getting paranoid.

Respondents in this study often gave mixed, incomplete and contradictory accounts of how cannabis use, paranoia and mental illness are linked.

**Table 49: Perception of experiences by drug use as a cause**

	I do have a mental illness (n=7)		I do not have a mental illness (n=6)		Undefined (n=6)	
	n	%	n	%	n	%
<b>Drug use as a cause (n=19)</b>						
Yes	6	85.7	4	66.7	3	50.0
No	1	14.3	2	33.3	3	50.0

All the respondents in this study had been given a diagnosis of comorbid substance use disorder a part of the AESOP study yet not all of the respondents believed they had either a mental illness or a substance use disorder. Of those that felt they had or had had a mental illness, the majority saw drug use as 'the' or one of the causes of that illness. Interestingly, among those that did not see their experiences as a mental illness, the majority saw drug use as a cause of their experiences as well. Constructions of the relationship between cannabis and paranoia may help explain this.

Furthermore, not all respondents who saw a link between their substance use and their experiences thought that they had a problem with substances. For many respondents this is explained by cannabis use specifically not being seen as problematic (this notion is discussed below).

**Table 50: Perception of substance use by perception of relationship between substance use and mental health**

	<b>I do have a problem with substances (n=11)</b>		<b>I do not have a problem with substances (n=4)</b>		<b>Undefined (n=4)</b>	
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>
<b>Perception of relationship (n=19)</b>						
Substance use related to my experiences	9	81.8	3	75.0	3	75.0
Substance use not related to my experiences	1	9.1	1	25.0	0	-
Undefined	1	9.1	0	-	1	25.0

### **9.6.2 Illness causation, illness exacerbation and cannabis cessation**

When we unpack the relationship between substance use and mental illness further we see (as mentioned above) that if a respondent believed that they had a problem with substances that those substances were often not cannabis. Cannabis could still be related to paranoia and mental health but it was not always seen as problematic at least initially after the respondents' first illness episode. When drug use was considered a cause of experiences not all respondents considered cannabis to be the problematic drug. Five (n=5/13) respondents saw other substances as the cause of their illness. However three of these respondents associated cannabis with their mental health and constructed cannabis use as an exacerbator of symptoms or illness experiences.

Cannabis use in some cases wasn't seen as something that the respondents wanted to give up altogether either. All of the respondents used cannabis at some point since their initial episode that had brought them into contact with mental health services. Nine of the nineteen respondents saw their cannabis use as not problematic. Not surprisingly the majority of these respondents had continued (or simply changed) their cannabis use (n=6).

QS12, Lines 338-339 (Male, Black Caribbean)

Int: Did you ever feel at any point during your life that you had a problem with cannabis use?

Resp: I still don't see that I've got a problem now. It's an alright drug to have at the end of the day. It's better than the other things that are out there anyway. That has naturally come straight out of the ground, everything else is man-made isn't it?

Ten respondents, however, stated they had given up using cannabis altogether. Three respondents reported coming on and off cannabis. Two respondents reported that their drug use had changed, but it was only that they financially and practically had problems getting it.

**Table 51: Perception of experiences by changes in cannabis use**

	Substance use related to my experiences (n = 15)		Substance use not related to my experiences (n = 2)		Undefined (n = 2)	
	n	%	N	%	n	%
<b>Cannabis use (n=19)</b>						
Stopped cannabis use	10	66.7	0	-	0	-
Changed cannabis use	3	20	2	100	1	50
Continued cannabis use	1	6.7	0	-	1	50
Undefined	1	6.7	0	-	0	-

The majority of respondents saw a relationship between cannabis use and mental illness or illness experiences, however this relationship was not always seen as a causal one. One respondent who throughout his account often had contradictory notions of the relationship between drug

use and his experiences, described, (at least tentatively), an overall construction of a relationship between the two but it was a complex one. In this extract he is talking about the paranoia that he had been experiencing prior to his first hospitalisation.

QS18: Lines 136-141 (Male, Other)

Int: Did you have any idea of what was happening? Why it was happening? Did you think there was a reason why it was happening?

Resp: My understanding at the time was that these things can and do happen but not very often otherwise it would be well known. The reason was, prior to that time I'd taken some amount of, I think it was LSD where it kind of had...

Int: Similar effect.

Resp: Similar effect yeah and almost seemed as if that was happening when I was smoking cannabis.

Int: So did you put down those experiences to smoking the cannabis? Or did you think there was another reason?

Resp: My reasoning was that there was some kind of gate that stops normal brain, I guess neurology to perceive the world in that kind of way. Then LSD kind of opened those gates towards that perception if you like. (Laughter) And because that door had been swung open it became accessible with lesser potent drugs like cannabis. And because I was smoking quite heavily I started feeling that kind of effect or perception; however you might want to put it.

In this example the respondent constructs drug use as a mediator of his experiences. His experiences are seen as being able to perceive the world in a way in which 'normal' people cannot because of some biological inhibitor. His inhibitor was broken by the drug use which did two things, it allowed him access to an alternate view of the world and secondly made him oversensitive to the effects of cannabis smoking;

namely paranoia. Paranoia then is constructed as seeing the world in a particular way. LSD is seen as an enabler.

Fifteen respondents believed substance use (drug or alcohol) to be related to their mental health whilst two did not see the relationship. If we look at those who stopped using cannabis over the course of their illness (n=10), we see that all of them believed that substance use was related to their experiences or mental health but only seven believed cannabis use was problematic.

Beneath the complex surface of the relationship between drug use (or cannabis use) and illness experiences is the sometimes contradictory nature of beliefs about whether a drug is a cause of mental illness, an exacerbator of illness experiences and whether respondents felt they had a problem with drugs. A respondent may believe drug use to have been a cause of illness experiences or to be related to it, but it does not follow that the same respondent sees their drug use as problematic or that they stopped using drugs as is illustrated in Table 51 above and Table 52 below.

**Table 52: Relationship between cannabis use and perceived cannabis use problem**

	<b>Cannabis use possibly problematic (n = 9)</b>		<b>Cannabis use not problematic (n = 9)</b>	
	<i>n</i>	%	<i>n</i>	%
<b>Cannabis use (n=18)</b>				
Stopped cannabis use	7	77.8	3	33.3
Changed cannabis use	1	11.1	5	55.6
Continued cannabis use	1	11.1	1	11.1

## 9.7 SUPPORT, COPING AND EXPERIENCES OF SERVICES

The second aim of this study was concerned with how respondents with comorbidity constructed their experiences of treatment services. The interview topic guide asked specific questions about when respondents

came into contact with services, as well as what their expectations of services were before their first contact.

All of the respondents had contact with mental health services. However, only 9 respondents had contact with drug or alcohol services and only six of those respondents had received any consistent help. Because of the small numbers it was impossible to see if there were any patterns by gender or ethnicity. Three of the respondents had been referred to services or referred themselves to a substance abuse service, but had found after one contact that it was either unhelpful or inappropriate for them. Two of these respondents had been referred by mental health services. Of the six respondents that had notable input from drug treatment services four of them sought help themselves, and again most were organised through mental health services.

When describing the help given to them by services two main points became apparent; firstly nearly all respondents were focusing on the help mental health services provided and only talked about substance abuse treatment services when directly prompted to; secondly 'help' and 'recovery' were very difficult to disentangle. Respondents spoke mostly about hospital and medication when referring to the formal treatment they had received but help, support and recovery had blurred boundaries.

Themes around treatment incorporated aspects of the support needed (from friends and family as well as mental health services) and processes, goals or mechanism for how recovery was achieved. The mechanism hindsight was often evoked in accounts of treatment and recovery. Respondents described not thinking that they needed help or treatment at the time of their psychotic experiences. It was either during their hospital stay or as their illness progressed that they realised they had been helped and that it was necessary at the time it occurred.

This section below looks at constructions of hospitalisation, which were distinct from other aspect of treatment and recovery, who

respondents felt were responsible for providing treatment and support, and how they felt this could be achieved.

### **9.7.1 Hospitalisation**

Constructions of hospitalisation were elicited in two ways: respondents drawing a parallel between hospital and prison; and respondents describing the role or benefits of having been in hospital.

#### **9.7.1.1 Inside vs. Outside: The prison parallel**

The theme 'inside vs. outside' describes what respondents felt it was like being in hospital and then re-entering the community. For example, in two accounts respondents talked about needing to keep links with the hospital before completely re-entering their old life. Others gave constructions of the difficulties of orientating themselves to the 'world outside' after being in hospital.

QS15, Line 533 (Male, Black African)

Resp: Just me coming out of hospital and trying to get back into society. It was like – it kind of brought me down again. Confidence.

The largest part of this parallel was called 'the prison parallel'. Here respondents constructed their experiences of being in hospital as similar to being 'locked away'. Conversely leaving hospital was construed as either escaping or finally gaining their freedom.

QS17, Lines 182-189 (Female, Black Caribbean)

Int: Can I ask you, do you remember? Well the first time you went into hospital your Mum and your Aunt took you really didn't they? And the second time, did you go on your own or did your Mum take you?



Resp: I think every time... Do you know what it is yeah? It's like, my Mum called the police. Because back in the day you could police and they could section you. They could take you straight there. It was without you being seen by a psychiatrist. But I think the second time I think I was at my Mum's house and she just called them and they came and took me. And that happened a good three times, I've been taken from my Mum's house. We're risking the ratings and everything. Proper.

Int: Did you live with your Mum for a...?

Resp: Yeah. And every time she thinks I'm going funny. Or call the psychiatrist to come and see me. And obviously because I've got a record, they automatically think, yeah, yeah. That's why I escaped from hospital one time and I didn't go back.

Int: Because you have a record?

Resp: No not record. I mean... because...the mental..

Int: Because you've been to services before they just think...

Resp: Yeah.

Constructions of punishment and force also formed part of this theme.

QS13, Lines 225-226, (Male, Black Caribbean)

Int: You said when you started smoking again and your mum would notice, and so then she'd take you to hospital. Do you think those times that you needed to be in hospital?

Resp: Yes, because I need to understand that smoking weed is not good is it? So it's like going to jail, you do a crime you've got to do the time haven't you? So the same thing.

Behaving how the hospital expected you to or following the rules was a prominent feature for six respondents who talked about their experience of being hospitalised as is evident in the following extracts.

QS15 Lines 486-489 (Male Black African)

Int: And how would you describe your experience of being there, in your own words?

Resp: At first it was scary, but then I started to get more understanding as the years went on. They're just there to help you.

Int: How did you feel you were treated by the people there?

Resp: At first I thought I was [inaudible], but then they just see you and they're restraining me all the time, and I got angrier and [inaudible]. As the years went on I started to have more of an understanding about why they was doing that, and I started to go by the rules, then things got better.

Eighteen of the respondents had been hospitalised at some point since their initial episode of 'illness'. Table 53 shows that ten of those respondents had at least one compulsory admission. Regardless of whether a respondent was compulsorily admitted or not, they still saw hospital as an institution which they had been forcibly placed. Respondents gave constructions of having to 'serve their time' there before they were released.

**Table 53: Respondents who paralleled hospitalisation to prison by respondents who had had a compulsory admission**

Hospitalisation compared to prison (n=16)	Ever had compulsory admission			
	No (n=8)		Yes (n=8)	
	n	%	n	%
No	2	25.0	2	20.0
Yes	6	75.0	8	80.0

The findings of the quantitative study showed that for patients with White or Black Caribbean ethnicity those with comorbidity had a significantly higher likelihood of having a compulsory admission than those with no drug use. This pattern was not observed in Black Africans. There were no notable differences in respondents from the qualitative study by ethnicity and compulsory admission, however all but one of the females had a compulsory admission. Use of the theme prison parallel was equally spread across ethnic groups and by gender.

#### 9.7.1.2 The role of hospitalisation

Sixteen of the respondents expressed views about the role or usefulness of hospitalisation. Six respondents felt that hospital did not provide any form of support or help (mostly prompted responses) to them however the remaining respondents who experienced hospitalisation gave at least one way that hospital helped them in their recovery process. Table 54 summarises the uses described by the respondents. Resting from the stresses of life was one of the most common perceived uses or benefits of being hospitalised (n=6) and was elicited only in prompted form.

**Table 54: Usefulness of hospitalisation**

	prompted		unprompted	
	<i>n</i>	%	<i>n</i>	%
<b>Usefulness of hospital (n=16)</b>				
Think about things	1	6.3	0	-
Stop using substances	1	6.3	0	-
Acting out	0	-	1	6.3
Support	2	12.5	3	18.8
Rest	5	31.3	0	-
Not being in prison	4	25	0	-
Safety	2	12.5	2	12.5
None	5	31.3	1	6.3

**Table 55: Usefulness of hospital by respondents who had had a compulsory admission**

	Ever had compulsory admission			
	No		Yes	
<b>Usefulness of hospital (n=18)</b>	<i>n</i>	%	<i>n</i>	%
None	2	25.0	4	40.0
Some	4	50.0	6	60.0
No opinion	2	25.0	0	-

Interestingly of the ten respondents that found hospital useful over half had been sectioned at least once during their illness. This suggests that even when a patient is hospitalised against their will, they may see the overall benefit of being in hospital afterwards.

### **9.7.2 Who: Constructions of who gives support and who is responsible for the treatment journey and recovery process**

All respondents gave constructions of who had supported them or should be responsible for supporting them through their treatment journey and recovery process. There were four main sources of support described by the respondents: Health services; spiritual or alternative means; local communities; and self-support. The majority of respondents (n=12) believed that mental health services was the right place for them to receive treatment and six respondents actively used mental health services as part of their larger coping strategy. All of the responses under this theme were prompted.

Despite all of the respondents having been given a diagnosis of comorbid substance use disorder in the first arm of the PhD study only nine of them had had contact with substance abuse treatment services. Of these nine only five respondents actually felt drug or alcohol treatment services were a place where they would go for help.

**Table 56: Sources of support during treatment and recovery**

	prompted		unprompted	
	<i>n</i>	%	<i>n</i>	%
<b>Sources of support (n=19)</b>				
Health services (n=13)				
Mental health services	12	63.2	0	-
Drug treatment services	2	10.5	3	15.8
GP	5	26.3	3	15.8
Wider society (n=4)	0	-	4	21.1
Family or friends (n=14)	11	57.9	3	15.8
Spiritual/Alternative (n=8)				
Church/Bible	6	31.6	0	-
Herbalism/Alternative therapy	2	10.5	0	-
Oneself (n=14)	0	-	14	73.7

Eight respondents described turning to spiritual or alternative forms of support during their treatment or recovery process. The majority of these respondents were from a Black ethnic group (n=6). None of them however felt that this was a permanent source of support for them.

All but five respondents talked about the role that they themselves played in their recovery process and these constructions were elicited in only unprompted form. The role that the respondent played was constructed in several ways: the strength they had to evoke during their recovery; having to rely on themselves because they did not have others as a source of support; initiating interventions themselves; and the coping strategies they employed during recovery. I will discuss this in more detail below in the discussion of the theme on mastery and involvement in the treatment journey.

Family and friends were also seen as a support. Fourteen respondents felt that their family member's involvement in their treatment and recovery was a source of support. However respondents typically gave both positive and negative examples of family involvement. Additionally seven respondents gave constructions of not wanting to put upon their family or understanding that family members had their own problems. Two respondents talked about not having anyone to talk to.

Eight respondents spoke of the role of their GP. In all but one account GPs were approached as an initial resource, in a crisis and often because of persuasion by family members who were trying to help them at the time. Four of the respondents gave unprompted descriptions of the role that wider society or social systems should play in supporting people with mental health. These constructions often included the belief that larger social institutions such as the police, education and health systems as well as local community should play a role in supporting and monitoring people who have mental illness or who are at risk of having a mental illness. The role of social systems in society was seen as preventative.

#### **9.7.2.1 Credibility, professionalism and trust in the treatment process**

Although the hospital and community mental health staff were not a primary focus of research questions and did not form part of the topic guide, nearly all of the respondents who talked about their experiences of hospital, mental health or drug treatment services talked about the staff members involved in their treatment. Experiences were very mixed; most respondents experienced good and bad health professionals; some respondents (n=7) felt that staff members (often specific people) had been very helpful and supportive; others gave constructions of feeling that at times they were not understood, respected or supported (n=9). Consistency in health professionals was also very important (n=9). Regardless of whether they had positive or negative perceptions of the health professionals that treated them they all gave constructions of the credibility of health professionals as part of their overall construction of their treatment and recovery process.

### **9.7.2.2 Family roles and involvement**

As we saw in section 9.7.2, 14 respondents believed family and/or friends to be a source of support in their treatment and recovery journey. The majority (n=9) of respondents gave construction of the involvement of family members and significant others as sometimes positive and some negatives.

Positive involvement on the whole included family members giving emotional and practical support (such as talking about problems with respondents or providing physical care), but also included encouragement to seek help and paying attention to changes in the mental state of the respondent.

QS14 Lines 474-481 (Female, Black Caribbean)

Int: You're with her Dad?

Resp: Yes.

Int: How long have you been together?

Resp: It is about eight years. Yes, about eight years.

Int: And is he a support to you?

Resp: He's a fucking arsehole! No, he's all right! He knows about my illness and everything else. He would never let me smoke weed again. He would tell me if I was getting unwell or whatever.

Int: Do you talk to him about stuff – about your feelings or thoughts?

Resp: Yes, we used to. But there is nothing really to talk about because my thoughts are all right. If I am stressed out or upset then I will let him know.

Interestingly, negative involvement was mostly related to monitoring the respondents behaviour and in a number of the

respondents' accounts (n=3) was associated with taking away control and mastery in recovery (including normalisation of the respondents' life post illness episode). While in two respondents' accounts behaviour monitoring created a situation where the respondents did not want to talk to family members for fear of being re-hospitalised.

**Table 57: Family involvement in recovery process**

	<i>n</i>	%
<b>Family Involvement (n=19)</b>		
Family involvement considered positive	5	26.3
Family involvement considered negative	5	26.3
Mixed view	9	47.4

Support from family and friends was considered important but good relationships irrespective of the respondents' experiences and problems were key. For one respondent (QS1) this was being able to talk to his mum when he had his experiences and after he left hospital but he also described the importance of their continued good dynamic after his initial episode. This continued support was built upon the pre-existing family structure and relationship the respondent had with his mum.

This can be contrasted with respondents who did not have or want support from their family. For example respondent QS11 had lost his parents just before his initial psychotic episode and although fairly close with his siblings he described not wanting to put upon. He did not have a strong pre-existing familial support system to draw on in a time of crisis. Subsequently he gives an ambivalent construction of the support his siblings gave him.

QS11 Lines 106-111 (Male, Black African)

Int: And do you feel that they [the respondent's brothers and sisters] supported you when you were in hospital?

Resp: Yes and no. Yes and no. You know what I mean, you know cos remember they've got their own lives to lead as well. And remember two of my brother have had a nervous break-down as well.



This respondent and respondent QS14 both constructed the involvement of at least one family member as (at least in part) undesirable at least once in their accounts. Interestingly both of these respondents had family members with a history of psychosis.

### **9.7.3 What: Constructions of what is useful, needed and strived for in the treatment journey and recovery process**

As part of respondents constructions of their recovery and treatment pathways, respondents described what they felt had been useful or what they felt they had needed for recovery. Three types of support were identified: Psychological; social; and medical. Constructions of the usefulness of support systems and processes needed for recovery came mostly in prompted forms (with the exception of psychological support) as questions relating the usefulness of hospital and community services had been directly asked during the interview. In addition, the majority of respondents detailed other forms of support and recovery processes, as well as give indications of what mental health professionals helped them with during their time as both an inpatient and outpatient.

Table 58 shows the types of help and support that mental health professionals, friends and family gave respondents, as well as the range of recovery processes that the individuals evoked themselves. Help and support given from treatment services came in the form of formal therapy from counsellors or psychologists for seven respondents. Similarly 13 of the respondents identified that help from health professionals to understand or cope with the causes of their experiences, such as bereavement or drug use, was a useful form of support. In terms of support that health professionals, friends and family could provide, talking through the problems (n=14), economic support in the form of help with paying bills and getting benefits (n=3) and generally having other people around so they do not being by yourself (n=6) were all

mentioned. Equally 16 of the 19 respondents identified taking medication as a way of helping them recover from illness experiences.

**Table 58: Types of support and means for recovery**

	prompted		unprompted	
	<i>n</i>	%	<i>n</i>	%
<b>Types of support (n=19)</b>				
Psychological (n=19)				
Therapy	7	36.8	0	-
Talking about problems	6	31.6	8	42.1
Change in thinking process	4	21.1	12	63.2
Dealing with the causes of experiences	3	15.8	10	52.6
Social/Practical (n=14)				
Practical support	10	52.6	2	10.5
Not being by yourself	2	10.5	4	21.1
Economic support	0	-	3	15.8
Medical (n=16)				
Taking medication	14	73.7	2	10.5

One of the categories of psychological support that was elicited in accounts was psychological therapy. This construction was found in prompted form in accounts (n=7).

In exploring the relationship between perception of experiences and the identification of therapy as a useful tool in treatment and recovery, the majority (n=5) of respondents who felt they had a mental illness did not identify therapy as useful or potentially useful. For the majority of respondents who did not feel that their experiences constituted a mental illness, therapy was mentioned as a beneficial treatment in their account (n=4,). Additionally, 14 respondents identified talking about problems as a useful mechanism for coping or as a source of support but not all of these respondents felt this had to be done in the form of formal therapy (see Table 59).

**Table 59: Relationship between usefulness of talking about problems and having therapy**

	Talking about problems useful			
	Yes		No	
	<i>N</i>	%	<i>n</i>	%
<b>Therapy useful (n=19)</b>				
Yes	5	35.7	2	40.0
No	9	64.3	3	60.0

### 9.7.3.1 Normality

The sub-section below addresses how respondents constructed their own personal aims in treatment and recovery. While the topic guide did not ask specific question about goals in recovery, all respondents constructed the psychological, social and medical ways support was given or needed in the treatment journey and recovery process. These types of support all had one goal for respondents: Being normal.

Normality was constructed in two ways. The first involved constructions of the benefits of doing 'normal' things such as using the gym while in hospital or having a CPN help you begin to interact with the 'world outside' while on leave. The second involved the respondents' descriptions of trying to return their emotions or behaviour to state they were in before they were ill: the true or normal version of themselves. This was done through involvement in 'normal' activities. This was evident in QS4's account when he described the weeks following his admission to hospital as the beginning of getting back to 'being myself again' 'Doing normal things' was an important indicator of mastery in the recovery process.

QS14, Lines 241-242 (Female, Black Caribbean)

Int: What do you think makes you better?

Resp: When I start doing something with myself – like going to college. I have done a lot of courses – or started them. When I am low, that is what I normally do: go to college, meet people, force myself to get out and have a routine. That is what gets me better – having a routine. Something to do. Yes.

#### **9.7.4 The role of The Self: Constructions of mastery in treatment and recovery**

The research questions that have been outlined in Chapter 6 and the beginning of this chapter are concerned with uncovering how respondents with an 8-12 year history of psychosis and comorbid substance use construct their experiences. The themes that have been discussed above have aimed at detailing the constructions and patterns of constructions in respondents from different ethnic backgrounds, and have specifically focused on psychotic experiences and substance use. We have also looked at how respondents with comorbidity construct their experiences of mental health and substance use disorder treatment services which included unpacking the things that were salient to them in the treatment and recovery process.

In all respondents accounts it was clear where they placed 'the self', this often manifested in what role they felt they had to play in their recovery process and forms an important part of understanding the constructions of experiences given so far.

##### **9.7.4.1 Active and passive involvement and control in the treatment and recovery process**

When respondents talked about their experiences of hospital and other treatment services which have been discussed in the above sections they spoke of the role they felt they themselves should or did play in their own recovery process. Mastery in the recovery process can

albeit crudely split into two camps; active involvement, and passive involvement. At different times, nearly all respondents gave descriptions of active or passive involvement in their treatment pathway, symptom management or substance use (n=17).

**Table 60: Involvement in the treatment process**

	prompted		unprompted	
	n	%	n	%
<b>Involvement in treatment (n=17)</b>				
Active involvement	8	47.1	8	47.1
Passive involvement	8	47.1	7	41.2

Active involvement in the recovery process included respondents initiating contact with services for the things they were experiencing or whether they were involved in the medical aspects of their treatment. The latter included having control over the medication they received as well as researching and trialling alternative means of treatment such as herbal remedies. The majority of the respondents felt that they had taken an active role in their recovery process (n=16).

Initiating interventions was the main theme under active involvement. In 10 of the 19 accounts, initiating an intervention was discussed. These types of constructions did not vary by ethnicity, but only one of these accounts was from a female respondent. Respondents were asked questions about what happened around the time of their first contact with services, as well as if they had ever sought out help for their experiences or drug use. Four respondents gave prompted constructions of initiating interventions for themselves, but there were also examples from six of the respondents that were unprompted.

QS11 Lines 38-41 (Male, Black African)

Resp: So I'm on the right course. And during this period, I've completed ruts.

The six step detox. I've applied to go into rehab so that I can come out equipped with tools to maintain abstinence and also to help me change my behaviour and attitude and make personal choices and social interactions and confidence and all these sorts of things. So this is the

only time throughout my whole time of committing offences and using drugs that I personally, not the system, I personally have driven myself to the point where I'm saying enough is enough.

Challenging treatment procedures and individual staff members was another theme that was elicited in accounts about treatment. Data under this theme included examples where the respondent was deliberately difficult and challenged staff either actively (verbally/physically) or passively (not doing things they were asked to do). In many of these constructions, respondents were speaking about challenging the medication they were expected to take, and often challenging the system or individual health professionals happened when they were first in hospital and/or suffering acutely from their psychotic experiences. Respondents also gave examples of being challenging after they had 'settled' into hospital life.

QS6 Lines 61-66 (Male, Black Caribbean)

Resp: When I first went in it was alright, I met new people and whatever. And I started to feel a bit better in myself. I had some ups and downs with the staff, with their attitude and the way they were approaching me. So I kind of like, maybe I should have just settled down a bit. I kind of like aggravated things.

Int: Like what, what do you mean?

Resp: Well, there was an incident where I was in the smoking room with a friend, one of the other patients. And the patient slammed the door behind the staff. And then the staff came and said "Who slammed the door?" You know raising his voice. And "Who kicked the door? You're here on a prison section - we'll send you back to prison."

Int: The staff said that?

Resp: Yes. And after that I kind of like, every time we had a meeting or anything I would start saying things about the staff. About they're not treating us right, and things. I just got into arguments all the time with the staff really. Two or three. And the same staff that I had the arguments with were quite helpful anyway.

Eight respondents described behaving in a challenging way while in hospital or in contact with mental health practitioners. Only a handful saw this as a bad thing in retrospect, instead they often justified the behaviour. As seen in Table 61, only two of the respondents were White. This is consistent with studies that have looked at ethnic differences in health service utilisation and who have argued that Black patients are often seen to be more aggressive and may be more likely than whites to refuse procedures recommended by their physicians (McBean & Gornick, 1993; Williams 1998).

**Table 61: Challenging treatment by ethnicity**

	White (All) (n=7)		Black Caribbean (n=7)		Black African (n=3)		Other (n=2)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
<b>Challenging treatment</b>								
Yes	2	28.6	5	71.4	1	33.3	0	0
No	5	71.4	2	28.6	2	66.7	2	100.0

Related to challenging treatment processes was a theme at the heart of the over-arching theme mastery: control in the treatment and recovery process. This theme related to whether respondents had felt they had control, or should have had control, over aspects of the recovery process from formal inpatient and outpatient treatment to individual coping strategies for symptom management. It included respondents' conceptions of their decision making processes and having ownership of their recovery (e.g. control over whether or not to take

medication and subsequently have control over their symptoms, experiences or medication side effects).

All respondents gave constructions of the importance of control in treatment, regardless of whether they had active or passive responses to their treatment, management of psychotic experiences or substance use. Fourteen of the respondents detailed control over the medication they received (mostly not wanting to take it) as an important aspect of control in treatment. The need for control was mostly related the need for empowerment in a situation where they had no control, such as in hospital on section. However, in 4 accounts (two females and two males) the decision not to take medication was taken to protect another aspect of their self and their life choices, namely having children.

QS14 Lines 199-200 (Female, Black Caribbean)

Int: ...And you had been taking your medication regularly?

Resp: Not really, no. Because when I was – because in 2006 I didn't take any. I wanted to fall pregnant with her, so I am on and off with it. I take - at the moment I am not taking any sodium sulphate, or whatever it's called, because I am hoping to fall pregnant again, so I can't take that whilst I am doing that. So I am just on Olanzapine but a very low dose – 5 ml. But I find that that is all right for me, so when I talk about my medication, whether or not I do get pregnant or whatever, because I don't think... in the past I have been on 25mls of Olanzapine or 1000mls of sodium sulphate, but I don't believe that is necessary. Because some days I won't take it and I am all right. So, I believe that that should be reviewed in the next three months or something.

Two themes that related to more passive involvement in the recovery process where, 'resigning yourself' and '...because the professionals said so'. In both these themes respondents talked about taking more of a back seat in the recovery process. Respondents who gave constructions of 'getting on with it' or 'resigning themselves' (n=12) were nearly always talking about being in hospital or being on medication. In many accounts it was after initially challenging the



treatment service or the type of medication prescribed or even family that they became almost defeated and gave in.

QS17 Lines 115-116 (Female, Black Caribbean)

Int: Four weeks. And then you went to a community service after that.  
How did you find that?

Resp: I didn't find it very helpful. Not very, not too much. I was seeing a psychiatrist in Streatham. And I was like, I just went, I won't be in there. I was young. I was seventeen, eighteen. Just turned eighteen. I just wanted to get my life back on track. I weren't feeling going and being a mental patient. I still don't like it but, well, what could I do?

QS2 (Female, White) and QS6 (Male, Black Caribbean) along with four other respondents, had strong constructions throughout their whole account of settling into treatment because of the trust they had in mental health professionals, particularly their psychiatrists. From this theme it was clear that respondents believed 'The doctors know what they are doing' and you must trust that they are correct.

QS2 Lines 710-723 (Female, White)

Int: Was there any type of help either medication or therapy or something else any other type of help that you would have liked to have got then that you didn't perhaps?

Resp: You know I was completely unaware of it I would no not really. Not really.

Int: Ok.

Resp: Not really no very much trusted the system.

Int: Yeah.

Resp: And the you know the medical yeah I completely did again quite used to so I, I belong to that well that sort of people that thing that the doctor is there to help you and they will help you.

Int: Yeah.

Resp: And do anything to help you.

Int: Yeah.

Resp: Otherwise they would never have sworn that oath I don't know if you live with it raised with it.

Int: Yeah.

Resp: And that's what you see.

Int: No that makes sense.

Resp: That's what you expect from everybody from all the doctors and I was pretty sure and I was never given the reason to believe differently never so.

For a few of the respondents however 'because the health professionals told me' was conceptualised as them having to do something because they felt given all the options they had no choice.

#### **9.7.4.2 Understanding my experiences**

Constructions of mastery were related to understanding illness experiences and mental illness as well as its relationship to substance use. All respondents elicited constructions of the importance of understanding their experiences (both illness and substance use) during their treatment and recovery.

Understanding experiences was not considered the same as 'insight' into illness. For all respondents understanding their experiences meant making sense of them within their own model (i.e. not necessarily

a psychiatric model). Being able to judge when symptoms were reappearing or knowing how to manage experiences both formed part of understanding their illness.

QS17 Lines 225-226 (Female, Black Caribbean)

Int: Do you feel that the psychiatrists or nursing staff or key workers helped kind of explain to you what they mean by 'bi-polar?'

Resp: They've tried to tell me but it just goes in one ear and comes out the other. I just know when I'm manic, I'm manic.

Understanding experiences typically fell into two categories: understanding the cause of their experiences; and understanding the effects of substance use on their experiences. In both of these constructions health service staff were often the providers of information, however nearly all respondents who were hospitalised had trouble recalling whether this information had been given to them during their admission.

QS4 Lines 246-248 (Male, White)

Int: ...what did you think was going on with you why did you think you needed to go to hospital. did you think...?

Resp: Because I needed to sort of like get help to find out why, why, why this all happened and what the causes were and stuff and having someone to talk to and, and the support really.

Understanding experiences was also considered something that respondents had to learn for themselves, either by researching their illness and its relationship to substance use or just being emotionally ready to hear information that health service staff gave them about their experiences and the negative effects of drug use.

QS9 Lines 328-329 (Male, White)

Int: Can I ask you actually, before you came into hospital the first time, did you have any kind of perception about what mental illness was?

Resp: Yes. I didn't think at the time when they said "Oh you've got mental health issues." I just thought "No, I haven't got mental health issues." Because I didn't class taking drugs as a mental health illness; but then when I looked into more I realised what it actually does to you, it affects your mental state, then it all sort of clicked.

**Table 62: Understanding experience**

	<i>n</i>	%
<b>Understanding experiences (n=19)</b>		
Information about illness experiences	14	73.7
Information about substance use and mental illness	10	52.6

For all respondents constructions of wanting information about their illness experiences or information about the relationship between substance use and their illness experiences were given in prompted form.

### **9.7.5 Coping**

Coping strategies formed a part of the constructions of treatment experiences and recovery for 18 of the 19 respondents. It should be noted that coping strategies were not directly asked about in the interview topic guide, and coping strategies were elicited as a secondary element of other thematic constructions, such as substance use behaviours and views relating to the usefulness of treatment services and the role of family and friends in recovery.

## **9.8 CONCLUSIONS**

The second phase of the qualitative study aimed to uncover constructions of psychotic illness experiences and substance use in a sample of individuals with a clinical diagnosis of comorbid psychosis and

drug or alcohol use disorders. From detailed thematic analyses of 19 accounts it was found that individuals with comorbidity used a variety of mechanisms to describe their mental illness, substance use and treatment experiences. These included:

- 'When' in time the description of the experience was located (e.g. what they thought at the time or what they think now);
- 'What' feature of the experience or event was the respondent describing and focusing on in their account (e.g. how they felt or what they did); and
- 'How' (or through what lens) the respondent created or gave the account of that experience or event (e.g. were they intellectualising their experiences or justifying their mental illness related behaviours)?

Analysis of these accounts showed that individuals with comorbidity constructed their experiences of 'psychosis' and drug and alcohol use as separate but related. Just less than half of the sample believed they currently had or had experienced in the past a mental illness. A minority of the respondents who did not construct their psychotic experiences as a mental illness did however believe that they had been suffering from depression (which was not considered to be a mental illness).

Lay models of causation of psychotic and other illness experiences were elicited in all accounts and broadly fell into four frameworks: Emotional/psychological; biological; spiritual; or a combination of the above. The majority of respondents used a combination causation framework (n=10) of illness experience and many respondents had different frameworks of causation for their initial episode of illness and subsequent episodes of illness.

The most common combinations of aetiological frameworks were life events or stress in addition to substance use for respondent's initial episode of illness and substance use and or medication non-compliance for illness relapse or exacerbation of symptoms. Black Caribbean respondents tended to use emotional or biological frameworks whereas

White respondents tended to have combined frameworks. Black British respondents used all frameworks except biological and they were the only ethnic group to use a spiritual framework.

Causes of initiation of substance use were conceptualised in three main ways: psycho-social; physical; and situational. However this was not a major theme in accounts. There were three thematic constructions of continuation or cessation after respondents' first episode of psychosis: Psychological; Economic/Legal; and Social. The psychological constructions of substance use after the initial episode of illness or mental health experience were closely linked with themes around mastery and involvement in the treatment and recovery process. The perception of cannabis use as not being problematic was also an important theme.

The relationship between psychotic and mental illness experiences and substance use was a major theme in all accounts: the relationship between cannabis use and paranoia being the most prominent construction. Nearly half of the respondents spoke about their drug use and experiences of paranoia. Using substances to self-medicate was a theme that related closely to constructions of coping and over half of the respondents detailed using drugs or alcohol in this way at some point since their first episode.

In answering the research question how individuals with comorbidity of psychosis and substance use disorders constructed their experiences of mental health and substance abuse treatment services the qualitative study found that support could come from several sources: including Mental health services, drug treatment services, GP, Wider society/local community, Family or friends, Church or from oneself.

Most respondents felt mental health services (including hospitalisation) were a useful form of support. There were no notable differences in respondents by ethnicity and compulsory admission, however all but one of the females had had a compulsory admission.

Despite hospitalisation being seen as useful it was often related to the feeling of being imprisoned.

Types of support was categorised in three broad ways: Psychological; Social/Practical; and Medical. The majority of respondents drew support in all three categories and 14 of the 19 respondents felt talking about problems was a useful therapeutic tool.

Many respondents believed having mental health services give them information about drugs was useful but mastering your addiction yourself was considered key. This often meant initiating treatment yourself despite it being offered by mental health services or GPs. For respondents that continued substance use this was done on the basis that they could stop if they wanted (i.e. may not have a problem) and so did not need help regardless of whether they saw a relationship between their symptoms and drug use.

A number of respondents described the role of their family in their treatment and recovery process. Involvement on the whole was considered positive although perceptions at the time of experiences differed from those viewed retrospectively.

The role of self and mastery in substance use, treatment experiences and recovery from illness was a salient theme and returning to 'Normality' featured heavily in accounts. Many respondents also draw comparisons both explicitly and implicitly between their own illness experiences and that of other patients.

## Chapter Summary 9.

### Chapter Summary

#### Aims of the Chapter:

To summarise the findings from Phase Two of the study in relation to the study research questions.

#### Key Points:

- Individuals with comorbidity used a variety of account mechanisms to construct their mental illness, substance use and treatment experiences
- A key construction throughout all accounts was lay models of illness aetiology
- The relationship between psychotic and mental illness experiences and substance use was a major theme in all accounts: the relationship between cannabis use and paranoia being the most prominent construction.
- Individuals with comorbidity constructed their experiences of 'psychosis' and drug and alcohol use as separate but related
- Using substances to self-medicate was a theme that related closely to constructions of coping
- Support networks were constructed as coming from several sources: including Mental health services, drug treatment services, GP, Wider society/local community, Family or friends, Church or from oneself.
- Perceptions of the role of family and friends was on the whole positive but current perceptions of involvement often differed from retrospective perceptions
- Mastery and returning to 'normal' was a key theme in the treatment and recovery process
- Comparisons both explicitly and implicitly between individuals own illness experiences and that of other patients were often drawn.
- Experiences of services were mostly constructed as a useful form of support (including hospitalisation).



## **CHAPTER 10: DISCUSSION**

### **10.1 SUMMARY OF FINDINGS**

#### **10.1.1 Quantitative results summary:**

The findings from the quantitative investigation support the hypothesis that the prevalence of comorbid substance use disorders (SUD) in individuals with an 8-12 year history of psychosis differ according to ethnic group and that the prevalence of comorbid substance use disorders is lower in Black Africans compared to Whites. However, the findings did not support the hypothesis that the prevalence of comorbidity is higher in Black Caribbeans compared to Whites.

When drugs and alcohol were looked at separately, significantly less drug and alcohol use as well as drug and alcohol use disorders (DUD and AUD) were found in Black African patients compared to White and Black Caribbean patients when potential confounders were adjusted for. Black Caribbans did not have an increased prevalence of DUD and AUD. Interestingly after adjustment, risk for drug use and use disorders in the Black Caribbean patients had a trend for being lower than in White patients. Risk for alcohol use and use disorders were significantly less likely in Black Caribbean patients compared to White patients.

The second hypothesis that comorbidity is negatively associated with psychotic relapse and hospital admission in all ethnic groups was not supported.

Despite the negative finding relating to prevalence of comorbid SUDs in Black Caribbean patients, a trend of increased likelihood for negative outcomes (i.e. episodic or neither episodic nor continuous illness course, increased frequency of psychotic relapse, increased frequency of hospital admission and compulsory hospital admission), was found in

Black Caribbean patients with DUD. This pattern was not found in White patients. These findings did not reach statistical significance however.

Interestingly significantly lower risk for psychotic relapse in the comorbid DUD group was found in White patients and significantly lower risk for psychotic relapse was found in the alcohol use groups for Black Caribbeans. Black Caribbeans were also significantly less likely to have had several hospital admissions if they were alcohol users compared to never using alcohol.

Not surprisingly White patients with comorbid AUD showed a trend of higher rates/risk for negative outcomes (i.e. increased frequency of psychotic relapse, increased frequency of hospital admission and compulsory hospital admission) compared with patients from Black ethnic groups. These findings unfortunately failed to reach statistical significance. White patients with comorbid DUD however, were significantly more likely to have had a compulsory hospital admission (OR 4.435, CI 1.398-14.062,  $p=0.011$ ).

Black Africans who had a low prevalence of both drug and alcohol use disorders had significantly lower rates of psychotic relapse in the alcohol use and comorbid alcohol use disorder group (compared to non-users) (RR 0.162, CI 0.057-0.463,  $p=0.001$ ). Black Africans were also less likely to have frequent hospital admissions (comorbid DUD; alcohol use; and comorbid AUD) and compulsory hospital admissions (comorbid AUD only). This pattern was not observed in Black Caribbean or White patients. However these differences were only significant for frequency of hospital admission in the alcohol comorbid group (Alcohol use: RR 0.624, CI 0.367-1.061,  $p=0.082$ ; Comorbid AUD: RR 0.147, CI 0.029-0.748,  $p=0.021$ ).

### **10.1.2 Qualitative results summary:**

The second phase of the qualitative study aimed to uncover constructions of psychotic illness experiences and substance use in a sample of individuals with a clinical diagnosis of comorbid psychosis and drug or alcohol use disorders. It aimed to both describe if and how the problem of comorbidity differs for ethnic minorities in psychotic populations and to identify conceptualisations illness and substance use. The study also aimed to explore the impact comorbidity might have on attitudes towards the perceived usefulness of treatment approaches (namely hospitalisation, community treatment) and the role family, friends and alternative forms of support play in the recovery process.

From detailed thematic analyses of 19 accounts it was found that individuals with comorbidity used a variety of mechanisms to describe their mental illness, substance use and treatment experiences. These included:

- 'When' in time the description of the experience was located (e.g. what they thought at the time or what they think now);
- 'What' feature of the experience or event was the respondent describing and focusing on in their account (e.g. how they felt or what they did); and
- 'How' (or through what lens) the respondent created or gave the account of that experience or event (e.g. were they intellectualising their experiences or justifying their mental illness related behaviours)?

Just less than half of the sample believed they currently had or had experienced in the past a mental illness. A minority of the respondents who didn't construct their psychosis related experiences as a mental illness did however believe that they had been suffering from depression (which was not considered to be a mental illness).

Lay models of causation of psychotic and other illness experiences were elicited in all accounts. The majority of respondents used a

combination causation framework (n=10) of illness experience and many respondents had different frameworks of causation for their initial episode of illness and subsequent episodes of illness. Black Caribbean respondents tended to use emotional or biological frameworks whereas White respondents tended to have combined frameworks.

Reasons for initiation of substance use as well as changes in substance use were elicited in most accounts. There were no observed differences in gender, ethnicity, or whether respondents saw themselves as having a problem with substances in the frameworks of substance use initiation. The psychological constructions of substance use after the initial episode of illness or mental health experience were closely linked with themes around mastery and involvement in the treatment and recovery process.

The relationship between psychotic and mental illness experiences and substance use was a major theme in all accounts; the relationship between cannabis use and paranoia being the most prominent construction. Nearly half of the respondents spoke about their drug use and experiences of paranoia. Using substances to self-medicate was a theme that related closely to constructions of coping and over half of the respondents detailed using drugs or alcohol in this way at some point since their first episode.

The perception of cannabis use as not being problematic was also an important theme but was not always related to decisions to give up cannabis use. Many respondents believed having mental health services give them information about drugs was useful but mastering their addiction themselves was considered key. Seeing a relationship between relapse or symptom reoccurrence and substance use was related to respondents' decisions to stop using substances but this was tempered by a desire to continue using cannabis socially. Understanding the relationship between illness experiences and substance use was salient to most respondents but this tended to happen over time.

Support was considered to come from several sources: including mental health services, drug treatment services, GP, wider society/local community, family or friends, church or from oneself. Many respondents felt mental health services were a useful form of support but the majority gave constructions of the role they themselves played in their recovery. Hospital was mostly seen as useful. There were no notable differences in respondents from the qualitative study by ethnicity and compulsory admission, however all but one of the women had had a compulsory admission. A theme relating to the feeling of being imprisoned was associated with hospitalisation.

Types of support was categorised in three broad ways: psychological, social/practical; and medical. The majority of respondents drew support in all three categories and most felt talking about problems was a useful therapeutic tool. A number of respondents described the role of their family in their treatment and recovery process. Involvement on the whole was considered positive although many had mixed feelings.

The role of self and mastery in substance use, treatment experiences and recovery from illness was a salient theme and returning to 'Normality' featured heavily in accounts. Many respondents also draw comparisons both explicitly and implicitly between their own illness experiences and that of other patients.

## **10.2 METHODOLOGICAL LIMITATIONS**

### **10.2.1 General**

A major strength of the AESOP-10 study which the first phase of the PhD utilised data from, was that it was a large epidemiological study. Participant identification and recruitment procedures were standardised and data for the main outcome variables (diagnosis of psychotic illness and substance use disorders) were collected and collated using three different sources: patient interview, key informant (usually family

member) and clinical records. These were then assessed against ICD-10 criteria (following consensus meetings).

However, there are limitations to this phase of the PhD study that should be noted. Despite recruiting large numbers of FEP patients for the AESOP baseline study, and achieving a 90.4% follow-up rate for the AESOP-10 study, sample size was a limitation. A relatively small number of participants were diagnosed with a substance use disorder and numbers of patients with a substance use disorder from Black African ethnic groups were tiny ( $n=6$ ). This meant that it was not possible to conduct some of the adjusted statistical tests for Black African patients that were necessary to determine differences by ethnic group and to accurately address the study hypotheses. This has an impact on the generalisability of the study and reliability of results.

Differences in the sample characteristics between the two study centres were explored in sections 8.2 and 8.3. These differences might suggest data from each centre should be analysed separately and questions about pooling the data are raised. As the PhD involved only two study centres there was insufficient data to treat centres as clusters. For completeness and transparency stratified analyses by study centre were conducted alongside pooled whole sample analyses and stratified analyses by ethnic group to explore the effect comorbid substance use disorders has on risk for negative outcome.

Differences in the risk for relapse and hospital admission between non-substance users and those with comorbid diagnosis were found between the two study centres. These differences are most likely to do with differences in the ethnic distribution of the London and Nottingham samples however other sample differences (which may not have been measured) may have been present. Although the significantly smaller proportions of patients from both of the Black ethnic groups in the Nottingham sample meant data from both study centres needed to be pooled the stark study centre differences in the odds and rate ratios for

negative outcome highlight the limitation of pooling data and should be noted when interpreting the findings.

Furthermore it would be fair to argue that a better measure of frequency of compulsory admission would be to look at the rates of compulsory admission. However, a limitation of this study is that the data for legal status on admission to hospital was limited meaning that it was only possibly to look at compulsory admission in terms of its presence or absence over the follow-up period.

### **10.2.2 Bias**

The final sample for phase one of the PhD study excluded patients with a follow-up of less than eight years and patients that had moved abroad or died. The included sample had significantly less White males than the excluded sample. In addition analyses of the excluded sample showed that patients that had moved abroad tended to be from Black African ethnic groups. These differences are likely to have led to some selection bias.

Although substance use was measured using three sources in the AESOP-10 study information relating to drug use parameters, for example, frequency, quantity, duration and type (e.g. type of drug that was misused) of use were not available. It would have been of particular interest to investigate this in order to ascertain whether there is an association between quantity and frequency of substance misuse and negative outcome over time as demonstrated in studies looking at dose-response of cannabis and psychotic relapse (Linszen et al., 1994). Additionally it is possible that certain ethnic groups tend to have longer periods of substance use disorder or misuse certain types of drugs. Those differences may have explained differences in clinical outcome.

In addition the lack of corroboration of self-reported drug use and drug use identified through examination of clinical records with biological techniques such as hair or urine analyses may have led to bias (for example social views about drug use in certain ethnic groups may lead to increased or decreased likelihood of drug use disclosure). Previous studies have shown that hair analysis in patients with schizophrenia is a well-tolerated, sensitive test for substance use disorders and has several advantages over questionnaires and urine analysis for clinical and research purposes (McPhillips, Kelly, Barnes, Duke, Gene-Cos & Clark, 1997).

Although corroborated in the majority of cases by self-reported information, data relating to frequency of hospital and compulsory hospital admission were also limited. Information from clinical records was sometimes incomplete in relation to legal status on admission. A subsequent limitation of this study is that the data for compulsory admission over the follow-up period was limited the presence or absence of a compulsory admission and frequency of compulsory of admissions (which may have been different by ethnic group).

### **10.2.3 Chance**

Due to smaller than predicted numbers of patients with comorbid substance use disorders in the ASEOP-10 study a second power analysis calculation was performed to estimate the study power of the final sample. Looking at prevalence of comorbid alcohol use disorders (AUD), tests with a 0.05 two-sided significance level were found to have 98% power to detect the difference between White patients (Group 1) with 64% prevalence of comorbid AUD and Black African patients (Group 2) with 14% prevalence of comorbid AUD (unadjusted odds ratio of 0.093) when the sample sizes were 42 and 21, respectively (a total sample size of 63, which included those with no alcohol use and those with comorbid AUD). The study was found to have high statistical power in the alcohol



use group however power may not have been so high in the drug use group and subsequently may have increased the chance of a false rejection of null hypothesis (type II error).

#### **10.2.4 Confounding**

Confounding involves error in the interpretation. Confounders (which are factors that have a relationship with both the independent and dependent variables) if known, are often dealt with by stratification or adjustment in analyses. Confounders in the PhD study were selected based on previous research in this area.

Indicators of social disadvantage (e.g. housing, employment and education) and medication compliance were measured in the AESOP-10 study using the WHO Life Chart. However data was often limited and incomplete. A limitation of the findings relating to negative outcome was that measures of social deprivation, which has been associated with ethnicity (Brugha et al., 2004), substance use (Peck & Plant, 1986) and risk for psychotic illness (Harrison et al., 1995) as well as medication compliance were not controlled for.

#### **10.2.5 Reverse causality**

A major limitation of the PhD study relates to the nature of the data collected on substance use. The Life Chart gave an overall measure of drug or alcohol use in the lifetime before follow-up. Several issues with this need to be highlighted.

Firstly although information about the periods of substance use were collected for patients that scored for abuse or dependence a high proportion of this data was missing making meaningful analysis by ethnic groups could not be conducted. This leaves us with the unanswered

question, are their ethnic differences in the prevalence of substance use disorders prior to onset vs. after onset of psychotic illness?

Secondly, causality is also an issue here. We cannot make any inferences about causality without knowing first knowing whether a SUD preceded onset of psychotic illness or not. In addition, if there are ethnic differences in prevalence of SUDs before and after the onset of psychotic illness then do these difference account for ethnic differences in frequency of hospital admission (including frequency and likelihood of compulsory admission), illness course type and frequency of psychotic relapse? It is possible that certain groups of patients who experienced multiple hospital admissions or multiple relapses did so because of on-going and sustained substance misuse and once this is controlled for the ethnic differences may vanish.

#### **10.2.6 Methodological considerations of mixed method and qualitative research**

Reliability and validity are realist research evaluation criteria and so have often been considered inappropriate for evaluating qualitative research (Kelle & Laurie, 1995). The philosophical approach that PhD study took however was a subtle form of realism. Subtle realism as I discussed in Chapter 5 combines realist ontology with a constructivist or idealist epistemology. This theoretical combination is compatible with both quantitative and qualitative enquiry and facilitates the use of both these research methods in a mixed method design. Silverman (1993) proposes a number procedures within a subtle realist framework that can increase the validity of qualitative research; careful case selection, on-going hypothesis testing, inductive analysis, and quantifying through counting. He also proposes that reliability can be addressed through standardised methods for taking down field notes and transcribing taped interviews and by having peers review the data analysis.

In addition Corbin and Strauss (1990) argue that there are several criterion from which qualitative research can be evaluated including:

- Interrelating the collection and analysis;
- considering concepts as basic units of analysis (i.e. data is a conceptualisation of events not events themselves);
- developing and interrelating categories;
- using a constant comparison method (i.e. an incident is noted, and should be compared against other incidents for similarities and differences);
- making sure patterns and variations should be accounted for and process (breaking a phenomenon down into stages, or steps), built into the theory; and writing theoretical memos

(Corbin & Strauss, 1990)

A number of these procedures were undertaken during data collection and analyses including; piloting of the interview topic guide, making reflexive field notes and memos, using experienced organisations to transcribe the interview data; involving co-coders in the analysis process; and developing categories and highlighting typologies of themes by respondent characteristics in order to propose theory.

Moreover, reliability and validity are concerned with knowledge creation. As mentioned in Chapter 5, Hamilton (2002) has offered an alternative definition of knowledge: beliefs in which one can have reasonable confidence in their validity or truth. This definition falls in line with what Hammersley (1992) considers a 'common sense' understanding and consensual notion of what constitutes social knowledge. This standpoint is particularly useful when judging the validity or truth of such knowledge generated through research findings.

Hammersley (1990; 1992), has argued however that while the same criteria should be applied to both qualitative and quantitative research, there are some problems with the conventional criteria of

validity and reliability and that some modifications should be made. Validity for example, in part derives from the way a sample was selected.

Many of the limitations of the qualitative study were the product of the design which was largely determined by the timing of recruitment for the AESOP-10 study. The study used convenience sampling which may increase the likelihood of selection bias. A larger number of interviews with equal numbers of men and women and ethnic backgrounds as well as different age groups may have allowed for some degree of theoretical saturation. However the number of eligible patients from the AESOP-10 study that had been traced and assessed at the time of recruiting for the qualitative study was small and subsequently a smaller than anticipated number of eligible patients were approached for the qualitative study. The final sample was biased towards young men from White and Black ethnic backgrounds.

The PhD qualitative study was partly exploratory in design and as I've highlighted, based on convenience sampling. Interpretation of studies that use purposive or convenience sampling are limited to the population under study and it is important to bear this in mind when coming to conclusions about the study findings (Bernard, 2006). In other words they cannot be generalised to other areas.

### **10.3 FINDINGS FROM BOTH STUDIES IN RELATION TO PREVIOUS LITERATURE: CONNECTING THE DATA AND GENERATING HYPOTHESES**

One of the main aims of the qualitative study was to explore constructions of psychotic illness and substance use in persons with comorbidity. In exploring constructions the aim was to, in part, to explain (or generate hypotheses about), if there were ethnic differences in prevalence and outcome of comorbidity, why those differences may exist.

The study also aimed to help uncover some of the complexities of the lived experience of people with both disorders as well as highlight the need for further areas of investigation around clinical and service use outcomes, experiences of health services and the role social networks play in outcome and recovery.

### **10.3.1 Prevalence of comorbidity**

As with many of the studies reviewed in this thesis, the PhD study found ethnic differences in prevalence of comorbidity. Slightly lower rates of drug use and drug use disorders were found in Black Caribbean patients compared to White patients. This finding is similar to that of Cantwell et al., (1999), however rates were only marginally lower and these did not reach statistical significance. These findings may be explained by changing patterns in types of drugs used or alternatively by an increase in overall drug use disorders in psychiatric patients from a Black Caribbean ethnicity.

It is noteworthy that most other studies have failed to look at differences beyond the crude 'Black' and 'White' divide (e.g. Copeland et al., 2003; Ahuja et al., 2007; Strakowski et al., 1992) and differences between Black Caribbean and Black African groups were only explored in three studies in the PhD study systematic review. Consequently, the finding that Black African patients have a significantly lower prevalence of substance use disorder compared to White and Black Caribbean patient is a novel one. The small sample size in the Black African group should be noted when interpreting this finding however. In addition the study supported findings by Miles et al. (2003) that alcohol use disorders were more prominent in White ethnic groups. Similarly this finding was observed in an earlier study by Cantwell et al. (1999).

Studies such as Afuwape et al., (2006) have found equivalent rates of drug use disorder in White and Black Caribbean patients with psychosis. A similar observation was found in the PhD study however

after controlling for age, gender, diagnosis and study centre lower rates of comorbid DUD were observed compared to Whites.

Although the difference between Black Caribbean and White patients risk for drug use disorders was not statistically significant the prevalence of drug use disorders in Black Caribbean patients was observed to be much higher (40%) in this study than in other U.K studies which estimated prevalence between six and seven per cent (Cantwell et al., 1999; Afuwape et al., 2006). This may be due to the study not separating out Black patients that were British born. A study by Afuwape et al. found that when Black African and Black Caribbean groups were split into those who were British born and not, the Black British born patients had significantly higher prevalence (40%) of comorbidity than any other ethnic group (White = 6% and Black Caribbean = 7%), (Afuwape et al., 2006).

The qualitative study did not find any definitive observable differences between Black Caribbean and Black African individuals that might help explain the difference in prevalence of comorbidity. Moreover the samples of Black African patients in both phases of the PhD study were also too small to make any meaningful conclusions.

However findings from the qualitative study do highlight further questions around the relationship between comorbidity and ethnicity. In critique of one of the prominent theoretical models of comorbidity aetiology, drug use in the qualitative study (which was already present in most of the respondents) was constructed as one of the main causes of mental illness experiences.

We have seen that Black African and Black Caribbean groups have been found to have elevated risk for psychotic disorders (Fearon et al., 2006). In addition research has shown that in the general population drug use can be higher in some ethnic groups. If drug use was the sole cause of psychotic illness and Black Africans we would expect to see higher levels of substance use in Black African and Black Caribbean

groups. This was obviously not found in the quantitative study. Other factors such as negative events may also play a part in risk for psychotic illness however how these factors are interrelated with substance use needs further exploration.

How far does the aetiology of substance use help explain the aetiology of comorbidity? And leading on from that, could ethnic differences in the reasons for substance use help explain ethnic differences in prevalence of comorbidity?

Despite substance use being constructed as a causal factor in illness experiences, many of the respondents in the qualitative study described the initiation of substance use in response to what could be considered prodromal symptoms, such as depression. Others described initiation of a substitute substance as a way of managing other illness experiences such as psychotic phenomena (self-medication). Many respondents, however, described their early substance use in relation to situational factors suggesting initiation of substance use in comorbid populations is similar to that found in the general population. This finding is similar to that of Bradizza & Stasiewicz (2003).

These findings highlight the need to explore substance use course in relation to psychotic illness course. Because patterns of drug use before and after the initial index of illness were not explored in the first phase of the study and were not categorisable in the second phase of the study, it is difficult to unpick the role non-problematic drug use plays in risk for comorbid diagnosis. Although there were no observed ethnic differences in respondents' accounts of initiation of substances it is possible that ethnic differences in substance use patterns may play a role in explaining prevalence of diagnosable comorbid substance use.

One factor that is noteworthy in the discussion of ethnic differences in the relationship between substance use initiation and the risk for comorbidity is that, although cannabis use was not explicitly examined in the first phase of the study it was a significant theme in the

qualitative study. Moreover, data relating to the type of drug that led to comorbid diagnosis was not available in the quantitative study. Cannabis was found to be the most common drug used in the qualitative study and a proportion of respondents experienced problematic cannabis use. However, reasons for continuation and cessation of cannabis were different from cessation and continuation of other drugs or alcohol. In addition, although no ethnic differences in the use of cannabis were found it is possible that reasons for the initiation of cannabis use may differ by ethnicity.

A further question raised by the qualitative study is what role does social disadvantage play in ethnic differences in the risk for comorbidity? Detailed constructions of how respondents conceptualised their own ethnicity were summarised in section 9.2.2. These constructions were framed within a person's nationality, colour or religion. Furthermore all respondents gave constructions of the difficulties leading up to their first episode of psychosis and questions around unfair treatment were also asked of all respondents.

Constructions of social disadvantage (for example difficulties with education, housing or occupation) were not expressed in any of the accounts in relation to larger constructions of ethnicity or as direct reasons for either illness experiences or substance use. Instead, general 'stress' and individual negative life events (such as losing a family member or friend) had much more prominence in accounts of illness aetiology and substance use. Interestingly however, difficulties with social relationships (most commonly intimate relationships) did form part of constructions of illness aetiology, substance use initiation and changes in substance use. As well as pointing to the obvious role of larger social networks in health beliefs, relationship status and social networks have been shown to be an indicator of social disadvantage (Morgan et al., 2008).

The role social disadvantage plays in the increased risk of minority groups having mental illness or substance use was discussed in section



2.3.4. Delineating this relationship was not a primary objective of the PhD study. However this relationship warrants further discussion. While Black Caribbeans have a higher risk for psychotic illness and cannabis use, findings from phase one of the study have shown that Black Caribbean patients do not have higher risk for comorbid substance use disorders than White patients. Equally Black African patients had significantly lower rates of risk for comorbidity compared to White patients. While social disadvantage may play a role in overall risk for comorbidity, these findings call into question social disadvantage as a mediating factor in the risk for comorbidity in minority groups (i.e. that social disadvantage which is more prominent in minority groups explains higher risk in minority groups for comorbidity).

Although social disadvantage may play a role in substance use problems, it is likely that individual life events and negative experiences and eventually self medication for mental illness symptoms may play a bigger role. These factors may not be more prominent in any one ethnic group. Consequently, reasons for ethnic differences in comorbidity and outcome remain unexplained.

### **10.3.2 Comorbidity, ethnicity and negative outcome:**

#### *Psychotic relapse*

A question raised by the quantitative study is why were substance use and substance use disorders in some ethnic groups found to be protective for having further psychotic relapses? The PhD study failed to measure differences between patients who had substance use disorder before their first episode of illness and those who developed them after. In a review of comorbid substance use disorders in patients with psychosis, Wisdom et al. (2011) observed that in many of the studies patients who adopted abstinence reduced their rates of relapse, whereas those who continued to abuse substances experienced increased rates of relapse. This observation would only help explain findings in the PhD

study where substance use was protective but comorbid SUD wasn't (as was the trend observed for Black Caribbeans in the drug group).

Similar to observations in a study by Drake et al., (2011), Wisdom et al. (2011) argued that it is possible that a significant proportion of patients who were using or abusing alcohol and other drugs before or just after their FEP may have reduced their substance use or became abstinent as a result of the trauma of a psychotic experience itself and/or the education they received about preventing relapses. With the increasing use and abuse of cannabis (in the general population and within psychotic patient populations) and an increasing body of knowledge suggesting a causal relationship between cannabis and psychotic illness, observations such as these may help explain patterns of relapse found in the PhD study.

One important note is that equivalent rates of relapse between drug users, those with comorbid DUDs and non-drug users found in the whole sample are explained by the higher rates of risk in Black Caribbeans and lower rates of risk in White patients. A failing of the study is that relapse rates in the Black African group only were not able to be examined.

Findings from the qualitative phase of the PhD study show that substance use (in particular illicit drug use) was firmly built into lay models of causation for the first episode of psychosis (initial illness experiences) as well as models of causation for illness relapse (subsequent illness experiences) in patients with comorbidity. These models may help explain ethnic differences in the rates of relapse found in the first phase of the study in a couple of ways.

Firstly, for a large proportion of respondents substance use was constructed as related to self-medicating symptoms leading up to first contact with services. These findings are similar to those of Bradizza and Stasiewicz (2003) (which examined differences between patients with SUD only and those with psychosis and SUD), who found self-

management and mastery of psychosocial stresses through self-medication of substances was key. Although the qualitative study observed this behaviour across all ethnic groups with both drug and alcohol use disorders it is conceivable that certain groups of patients are more likely to use substances in this way.

Secondly, and in contrast to observations found in the above studies (Drake et al., 2011; Wisdom et al., 2011), continuation of substance use was found in many respondents for some or most of the time period since their first episode. Cannabis (the most popular drug of choice), in particular, was considered fundamentally different from other drugs and despite many respondents having an awareness of the relationship between cannabis, paranoia and their mental illness experiences, discontinuation of this particular drug was (in many cases) not desired. The quantitative study failed to separate out cannabis use from other drug use and evidence has shown increase in comorbid cannabis use disorders in psychotic populations (Donoghue et al, 2011), which has significant implications because of the relationship between cannabis and psychotic illness. Although there were no observed differences in the continuation of cannabis use by ethnicity in the qualitative study, continuation of cannabis use may go some way to explaining higher rates of relapse in comorbid populations despite individuals constructing drug use as one of the causal factors in illness experiences.

It should be noted that in the qualitative study respondents constructed reduction or cessation of substance use as taking time and change in substance use behaviour was related to two factors: firstly understanding the relationship between substance use and symptoms themselves (mastery); and secondly being ready to cut down or stop. Attitudes to drug use and health belief in larger cultural and immediate social networks as well as objective and subjective perceptions of social disadvantage are also likely to play their part. However, explanations for ethnic differences in rates of psychotic relapse point more towards choice

of substance than indicators of social disadvantage. Especially as certain minority group ethnicity may indeed be protective (e.g. Black African).

Turning lastly to illness course, the findings from both studies beg the question, why would comorbidity be related to illness course? A trend of a slight increased risk for episodic or neither illness course type was found in patients with comorbid DUD and decreased risk for these two illness course types in patients with comorbid AUD (these findings were not statistically significant).

A study by Goswami et al., (2003) which looked at illness course in schizophrenic patients in relation to substance use course found that substance use course did not lead to poor illness course in schizophrenia. However, substance use increase did precede exacerbation of schizophrenia symptoms at first episode. Conversely decrease in substances did not lead to an increase or decrease of illness symptoms.

A critique of comparing this study to the PhD study is that firstly, it had very small sample (n=22) and secondly illness course was categorised as total time (in months) either psychotic, non-psychotic or in remission rather than by the pattern of illness course. It is plausible that substance use (which may go through periods of cessation as well as abusive use) over the course of a person's psychotic illness may lead to increased frequency of relapse and hinder remission from previous episodes. This pattern of use would ultimately result in an episodic type illness course which was observed in the quantitative study.

#### *Hospitalisation, sectioning, the criminal justice system and the role of the family*

Findings from the quantitative phase of the PhD show that patients in the Black African group who had comorbid AUD were found to have significantly lower rates of hospital admission than non-users. Equally this pattern was observed in Black Caribbean patients with alcohol use. This finding is in complete contrast to the unadjusted findings of Afuwape

et al. (2006), as part of the UK COMO study which found higher levels of admissions in Black African patients with comorbidity. Although the desire to continue to use cannabis after the index episode was found across all ethnic groups in the qualitative study, it is conceivable that this, alongside fear of rehospitalisation under section and the subsequent loss of power, control and feelings of being 'normal' experienced during previous admissions may go some way to explain why certain people who experienced comorbid SUDs (and may have experienced family or health professional monitoring of their drug use) avoid voluntary hospitalisation.

White patients with comorbidity however had significantly higher likelihood of having a compulsory admission than those with no drug use. This pattern was also observed in Black Caribbeans but not Black Africans. This finding again is somewhat different to the study by Afuwape et al. who found Black British patients with comorbidity to have the highest rates of compulsory admission and may be explained by a higher proportion of Black British patients in the Black Caribbean group than in the Black African group in the PhD study.

There were no notable differences in respondents from the qualitative study by ethnicity and compulsory admission, however all but one of the women had had a compulsory admission. Constructions of hospitalisation as being similar to being in prison were equally spread across ethnic groups and men and women, and the majority of respondents saw hospitalisation this way. What this does tell us is that regardless of ethnicity (or gender) whether a patient is hospitalised under section or not the feeling that they are 'under lock and key' is experienced. The qualitative study also highlights that even when patients experience sectioning the overall benefits of hospitalisation is still felt, albeit retrospectively.

Wisdom et al. (2011) found in their review of comorbid psychosis and substance use that one study reported significant differences in involuntary hospitalisations and arrests between drug abusers and non-abusers at baseline; however these differences were no longer significant

at follow-up (Archie et al., 2007). This may have been explained by patients becoming abstinent after their FEP which in turn reduced their rates of hospitalisation, whereas those who continued to abuse substances experienced increased rates of hospitalisation. As with the findings for comorbidity and psychotic relapse, the PhD study failed to measure differences between patients who had substance use disorder before their first episode of illness and those who developed them after, so this relationship could not be tested.

According to Zola's (1973) model of help-seeking, people may draw upon 'lay referral' systems (family, friends ) or engage in 'self-medication' or alternative therapies instead of or in addition to seeking help from professional medical services. What this model as well as similar models of help-seeking highlight is how culturally-shaped beliefs about illness in individuals as well as the conceptualisation of illness by significant others both play a part in the ultimate responses to illness and decisions to seek help (Morgan et al., 2004). Findings from the qualitative study which uncovered constructions of self-medication as a reason for initiating substance use before and after FEP highlight how substance use could be considered an alternative to hospital.

Factors significantly associated with compulsory admission in a study by Cole et al. (1995) were absence of GP or family/friends involvement. Burnett et al. (1999) similarly found that sociodemographic and service related factors were the most important in pathways to care at first contact. In the qualitative study for this PhD respondents described the role of their family in their treatment and recovery process.

Some respondents gave constructions of not wanting to rely on family to support them because of feelings of guilt. Substance use was sometimes hidden from family members and some of the respondents from Black ethnic groups' constructed worry about the burden on family, disliking family interference in the treatment process or acceptance of family members needing to lead their own lives as reasons for reduced

family involvement. Moreover, of the six respondents that had had contact with the criminal justice system during their illness (either in relation to or separate from hospitalisation), four were from Black ethnic backgrounds.

Although the frequency of these constructions was small and negative constructions of family involvement were mainly from Black Caribbean as well as Black African individuals, the findings may help explain higher rates of risk for compulsory admission in general as well as ethnic differences in service utilisation.

However, four respondents in particular spoke of their families as being a constant source of support during the initial stages of illness as well as subsequent episodes. Support during their treatment was part of this but relationships irrespective of the respondents illness were key. Being able to talk to family about problems, having family pay attention to indicators of illness relapse were all seen as positive in many accounts and in some cases preferable to hospitalisation and could arguably affect whether a person is admitted to hospital on a compulsory basis. In addition, respondents spoke of the role of their GP played. In all of these accounts GP's were approached as an initial resource, in a crisis but mostly by family members who were trying to help them at the time.

Thinking again about health belief models that involve social networks, and as I mentioned above, it is possible that the aetiological models of a person's illness or general beliefs around psychotic illness and substance use held by 'significant others' could go some way to explaining rates of compulsory admission in certain demographic groups.

For example, the hypothesis that comorbidity is associated with compulsory hospital admission was supported, but as with any hospital admission and psychotic relapse the relationship did differ by ethnic group. All patients, as well as patients in the White only and Black Caribbean only groups who were drug users or had comorbid drug or alcohol use disorders were more likely to have had a compulsory

admission. It was only patients in the Black Caribbean group with comorbid drug use disorders however that had significantly higher rates of compulsory hospital admissions compared with patients with no drug use. This pattern was not observed in Black African patients who were less likely to have had a compulsory admission.

Studies have shown higher rates of compulsory admission in Black Caribbean patients with psychotic disorders (Bhui et al., 2003; Morgan et al., 2005. Morgan et al. (2004) have argued that these higher rates could be explained by differences in the way Black Caribbean and White families respond to mental illness and may not only hinder voluntary help-seeking but increase the involvement of the criminal justice system in an individual's pathway to care. This argument would likely explain higher rates of compulsory admission in Black patients with comorbid substance use disorders.

In general the findings from the quantitative study showed a trend of greater risk of admission, compulsory admission and psychotic relapse in Black Caribbean patients with comorbidity despite the fact the prevalence of drug use disorders was equivalent to those from White ethnic groups. This finding is most likely explained by the interactions Black Caribbean patients have with their immediate socio-cultural environment (Morgan et al., 2004), and/or interactions with available health care services as well as perceived discriminatory behaviour within these services (Bhui et al., 2003).

Do social networks play a role in likelihood of hospitalisation? From the qualitative study it is clear that some psychosis patients try to avoid family involvement because of illness and drug use monitoring due to fear of forced intervention. This may result in reduced voluntary hospitalisation. Interestingly constructions of initiating interventions for themselves were not more prominent in one ethnic group.



### **10.3.3 Constructions of psychotic illness, substance use and the treatment and recovery process**

As Kinderman et al. (2006) found, 'self' was a salient feature of understanding illness in the qualitative phase of the PhD study. This finding is also in line with many of the studies reviewed by Boydell et al., (2010) who found that achieving identity through understanding psychotic experience was salient in young persons with FEP. Separation between ill behaviours and normal behaviours as well as describing similarities and differences between themselves and other patients were important aspects of illness constructions in the qualitative study.

Furthermore, the experience of loss in patients with comorbidity was built into lay models of causation of illness experiences (which often included bereavement), a finding that is similar to that of Bradizza and Stasiewicz (2003). As I discussed above models of aetiology were prominent in PhD study respondents' constructions. Similar to several of the studies outlined in the systematic review by Boydell et al. (2010) respondents tended to adopt multiple explanations over the course of their illness.

A number of respondents constructed their mental illness type experiences as depression and of equal importance they did not consider depression to be a mental illness. With more and more public awareness of depression this finding may indicate that people are happy to admit to a problem that is not considered a mental illness because it is more socially acceptable.

Bradizza and Stasiewicz (2003), who looked at differences between patients with psychosis and SUD and SUD only found that despite negative effects of substance use such as symptom worsening, patients with comorbidity may continue using substances and that substance use in psychotic populations can be just as enjoyable as it is in the general population. A similar finding was observed in this study.

Constructions of substance use after the initial episode of illness highlighted a perceived relationship between drug use and music scene which may have played a factor in both continuation and cessation of drug use. Cessation of cannabis use in particular was often considered difficult. In line with Becker and Maimon (1983) and Rosenbock et al.'s (1988) health belief model the respondents gave constructions of reducing or stopping cannabis use when they were ready; when they saw it as beneficial (often after several attempts of encouragement to discontinue use from mental health service practitioners); and when the difficulty was not greater than what was to be gained (e.g., retaining custody of children or reducing likelihood of readmission to hospital).

Moreover, in line with Leventhal's Self Regulatory Theory many respondents detailed being given medical advice about the negative effects of drug use on their mental health, however drug use cessation was only taken up when respondents were interested in improving their own health.

In addition to constructions of substance use as a self-medication strategy that has been noted in both epidemiological and sociological literatures (Khantzian, 1985 & 1997; Bradizza & Stasiewicz, 2003) this study found that substances were most often used in social situations and related to the desire to reaffirm social relationships. Coping strategies were also an important reason for initiating substance use and this is in line with findings from a recent study by Archie et al. (2013).

As Kinderman et al. (2006) noted patients may construct their illness behaviours as an extension of their personality and this was true for a number of respondents in the qualitative study (for example thinking or worrying more than usual, or getting angry because they have a temper). This may be important in understanding how patients relate to family, other patients and staff when first in hospital if they feel their behaviour has been misidentified by family and professionals. Challenging behaviour on the ward could arguably be explained by understandable frustration and fear at being compulsorily hospitalised

rather than continued psychotic symptomatology, and uncovering patients own constructions of illness behaviours may help engagement with mental health services.

In line with a study by Warfa et al. (2006), this study also found that mental health issues were addressed more thoroughly than substance abuse issues in patients with comorbidity and patients often used alternate means of support such as church and alternative medicine as part of their larger coping strategy and support network.

#### **10.4 CONCLUSIONS, IMPLICATIONS AND FUTURE RESEARCH**

There are a number of strengths and limitations of this PhD study. In conclusion though, mixed method design involving large longitudinal epidemiological and qualitative studies are an appropriate way of investigating the relationship between psychosis and substance use. A subtle realist philosophical approach is a useful way of bridging the gap between the two seemingly opposing research processes. Assuming a definition of knowledge as beliefs in which one can have reasonable confidence in their validity or truth, the study has attempted to generate knowledge by representing a truth that can be judged in relation to what is already known.

However larger sample sizes in future qualitative research in this area may be useful for uncovering more detailed ethnic difference in constructions of illness, substance use and treatment experiences in patients with comorbidity.

What the above findings collectively tell us is that ethnic differences in the prevalence of comorbidity are likely in populations of patients with psychosis. Patients with comorbidity are more likely to have certain negative outcomes however the extent of the negative effect comorbidity

has on these outcomes is likely to be greater in Black Caribbean patients with drug use disorders and White British with alcohol use disorders. For illness course type, relapse and hospital admission, drug use could be considered protective. These negative outcomes may be explained to some degree by constructions and models of illness, help-seeking (particularly the use drugs to self-medicate), mastery and the role of professional medical services and the family.

Offering talking based treatments are likely to be of benefit to this population particularly if they are focused around causes of illness and substance use. Patients with a clinical diagnosis of a comorbid substance use disorder may see they have a problem with drugs but may not necessarily feel they have an addiction and this distinction may be salient to them.

Moreover patients may feel that stopping or cutting down substance use should be directed by themselves and determination through their own desire. Having mental health services involved (for example giving information about drugs) may be considered useful but mastering problems with substances may be seen as key. This may mean patients initiating treatment themselves despite being offered help by mental health services or GP's. Treating professionals may need to consider that patients may feel and indeed may be in control of their substance use including patients that see a relationship (casual or otherwise) between their substance use and symptoms.

Patient constructions of the relationship between cannabis and paranoia may help explain drug use behaviours. Paranoia as a side effect of using cannabis was often given in this PhD study and paranoid experiences were in some cases explained in this way rather than as a symptom of mental illness. In reality it is possible for both to be true. Moreover drug use as a cause of experiences was found to exist in illness constructions even when respondents didn't believe they had a mental illness.

This finding may have strong treatment implications suggesting that someone does not necessarily have to subscribe to a psychiatric framework of illness to perceive a causal relationship between their drug use and their paranoid symptoms. If paranoid symptoms are framed within negative effects of drug use rather than symptoms of mental illness this might be a more acceptable model of understanding and more likely to give way to a change in health behaviour. Additionally looking at models of illness causation and how these may change over a patient's illness career may be useful when working therapeutically with certain patients.

An important factor for clinicians to consider is that for some patients, lack of trust over cessation of drug use could be considered damaging to the relationship between patient and treating health professional. Additionally, at the core of continued or discontinued drug use is the individual themselves. An approach much like drug treatment agencies which focus on clients being ready for change may be more useful in encouraging discontinuation of substance use particularly when patients may see help from mental health services (rather than drug treatment services) as preferable. Additionally the involvement of family members in the treatment and recovery journey of patients may need to be considered based on pre-existing familial relationships.

Several areas for further investigation have been identified in this study including:

- Patterns of substance use course in relation to illness course.
- Whether the role of social networks play a part in higher risk of negative outcomes in minority populations with comorbid diagnoses.
- Whether patients constructions of illness aetiology or substance use initiation may help explain risk for comorbid psychosis and substance use disorders.
- The role continued cannabis use plays in diagnosis of comorbidity.

Further research into the patterns of substance use over time in this population is needed to explain reasons for ethnic differences in prevalence and negative outcomes of patients with comorbidity. Further epidemiological research examining substance use patterns in comorbid populations as individuals age as well as further qualitative research comparing constructions of illness, substance use and treatment experiences in psychosis patients with and without diagnosed comorbidity may be useful.

## Chapter Summary 10.

### Chapter Summary

#### Aims of the Chapter:

To discuss the strengths and limitations of the PhD study. To discuss the findings from both arms of the study in relation to previous research. To discuss future research areas highlighted by the both studies but particularly the qualitative study as well as the implications of the findings from the PhD as a whole.

#### Key Points:

- The hypothesis that the prevalence of comorbid substance use disorders in individuals with an 8-12 year history of psychosis will differ according to ethnic group was supported.
- Risk for comorbidity was found to be lower in Black African patients compared to White patients. However risk for comorbidity in Black Caribbean patients was not found to be higher.
- The hypothesis that in all ethnic groups, comorbid substance use disorder will be associated with:
  - a) more frequent relapses and
  - b) more compulsory admissionsindependent of potential confounders, including age, gender, diagnosis and study centre was not supported
- In relation to the research question how do individuals with comorbidity of psychosis and substance use disorders construct their experiences of 'psychosis' and drug and alcohol use 8-12 years after their first episode? The PhD study found that several account devices are used to construct experience. Aetiology of illness is a key to understanding one's experiences as is general feelings of mastery and returning to 'normal'. Individuals with comorbidity may construct their experiences of 'psychosis' and drug and alcohol use as separate but related and often use substances to self-medicate
- With regard to the second hypothesis: How do individuals with comorbidity of psychosis and substance use disorders construct their experiences of mental health and substance abuse treatment services? Primary and secondary care health services play a part in the larger support network of individuals
- The perceived role of family, friends and other social support networks in the treatment process for 'psychosis' and substance use disorder was largely positive but current perceptions of involvement often differed from retrospective perceptions. Experiences of services were mostly constructed as a useful form of support (including hospitalisation).
- There are a number of strengths and limitations of this PhD study, however, mixed method design involving large longitudinal epidemiological and qualitative studies are an appropriate way of investigating the relationship between psychosis and substance use. A subtle realist philosophical approach is a useful way of bridging the gap between the two seemingly opposing research processes
- Further epidemiological and qualitative research into the changing patterns of substance use over a time in psychotic populations are necessary to uncover patterns of comorbidity.

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## **APPENDIX 1: DOCUMENTS FROM QUALITATIVE STUDY**

This appendices contains the ethical approval letter, participant information sheet, participant consent form and interview topic guide used in the PhD Qualitative Study;

Document 1: Ethical Approval Letter

Document 2: Participant information sheet

Document 3: Participant consent form

Document 4: Interview Topic Guide

**National Research Ethics Service**  
**Bexley & Greenwich Research Ethics Committee**

South London REC Office (4)  
Ranken House  
Queen Elizabeth Hospital  
Stadium Road  
Woolwich  
London  
SE18 4QH

09 May 2008.

Miss Jozella S S Hart,  
PhD Student,  
Institute of Psychiatry, Kings College London,  
PO Box 63,  
De Crespigny Park ,  
London,  
SE5 8AF.

Dear Miss Hart,

**Full title of study:** Qualitative Study of the Ethnic Differences in People with Comorbidity of Psychosis and Substance Use Disorder  
**REC reference number:** 08/H0809/8

Thank you for your letter of 24 April 2008, responding to the Committee's request for further information on the above research and submitting revised documentation, subject to the conditions specified below.

The further information has been considered on behalf of the Committee by the Chair.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

**Ethical review of research sites**

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	5.5	07 March 2008
Investigator CV	Jozella Hart	
Investigator CV	Dr Craig Morgan	
Investigator CV	Paul Fearon	
Protocol	4	22 February 2008
Participant Information Sheet	3	15 April 2008
Participant Consent Form	2	25 February 2008
Response to Request for Further Information		24 April 2008
Letter of Support	Paul Calaminus	21 December 2007
Letter of Support	Patrick Gillespie	17 December 2007
Indemnity Details		
Sample of Headed Paper		

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

08/H0809/8

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



**Mr Karim Hussain,**  
**Chair.**

Email: Chris.Ward@kch.nhs.uk

*Enclosures:* "After ethical review – guidance for researchers": SL- AR2

*Copy to:* Mrs Gill Lambert

## **QUALITATIVE STUDY OF ETHNICITY, MENTAL HEALTH AND SUBSTANCE USE**

Please read this carefully if you are interested in participating in our research project. You may like to discuss it with your friends or family. A researcher will explain what the study involves but please ask questions if you do not understand anything or if you would like more information. Your participation is entirely voluntary.

### **Participant Information Sheet**

About ten years ago you made contact with mental health services for the first time and very kindly agreed to take part in some interviews and assessments as a participant in the 'AESOP' study. Recently the 'AESOP' team re-contacted you as part of their follow-up study and were again very grateful for your time and help.

#### **Why have I been invited?**

We are now contacting you and other people who participated in the 'AESOP' study to ask if you would be interested in joining an additional research project. Participation is completely voluntary, and will not affect any treatment or care you are receiving, in any way. For this, we would like to invite you to take part in a one off face-to-face interview with one of our researchers, to discuss your experiences since you first made contact with services and your perceptions on the quality of mental health and substance abuse care, both in general and from your own experience.

#### **What is this research for?**

The aim of the research is to find out about the experiences of people who made contact with mental health services (and drug treatment services) about ten years ago. The research also aims to find out how

people who have used mental health (and drug treatment services) services perceive the role of those services.

### **What would taking part in the research involve?**

As we said before your participation is completely voluntary. If you are interested in taking part the researcher will then ask you to sign a consent form.

The interview will last for no more than an hour and a half. It will be held in an interview room in the Psychological Medicine and Psychiatry Department at the Institute of Psychiatry. You will receive £15, in appreciation of your time.

The interview would be very informal. The person who would interview you is Jo Hart, who is a researcher at the Institute of Psychiatry. She is totally independent of the services that you may receive care from now or have received care from in the past.

Anything you say in the interview will be confidential. With your permission the interview will be audio-taped. The tape will be transcribed by an administrator working for the team. When the tape is transcribed you will not be identified by name but by a code number. The tape will be kept securely and destroyed at the end of the project. We will analyse the transcript on computers in the department. If you decide to withdraw from the study any tape or notes made of the interview would then be destroyed, and would not be used in the study. Any comments from the interview that we quote in our final report will be anonymised.

### **What are the possible benefits, disadvantages and risks of taking part?**

The interviewer will ask you about your experiences of mental illness and drug use, which are sensitive topics. However, the interview would always be in your control: you could end it at any time, and you could 'skip' questions if you wanted to. If you decided after the interview that you didn't want to be in this study after all, you can tell the researcher.

There will be no direct benefit to you in taking part in the project, but we hope you will feel it is worthwhile, and that your contribution may help to improve the care offered to other people in the future.



**If you feel you might agree to be interviewed, what should you do next?**

If you would like to participate in the study, you would like to ask any questions or want to find out about anything else at all, please telephone Jo Hart on 07779729589 (see further contact details below). If she is not there when you call, please leave a message and she will call you back as soon as she can.

If you decide to participate you are still free to withdraw from the study at any time, without giving a reason. Withdrawal from the study will not affect any treatment or care you are receiving.

We are happy to send you a copy of the report if you would like one. It is hoped that the results of the study will be published in a mental health journal. The study is funded by the Medical Research Council as part of the interviewers PhD. The project has been approved by the Bexley & Greenwich NHS Research Ethics Committee.

If, you decide to participate in the study and have a concern about any aspect of it, please speak to Jo Hart who will do her best to respond to your concerns (07779729589). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from Patient Advice & Liaison Services (PALS) at the Maudsley (0800 731 2864). In the event of you suffering any adverse effects as a consequence of your participation in this project, you may be compensated through the King's College London's 'No Fault' Compensation Scheme.

For further information about the project please contact:  
Jo Hart, PO Box 63, Institute of Psychiatry, De Crespigny Park,  
London, SE5 8AF. Tel: 07779729589 E-mail: jo.hart@iop.kcl.ac.uk

Study Number:

Participant Identification Number for this project:

## **CONSENT FORM**

Title of Project: **QUALITATIVE STUDY OF ETHNICITY, MENTAL HEALTH  
AND SUBSTANCE USE**

Name of Researcher:

Please initial box

1. I confirm that I have read and understand the Participant Information Sheet dated ..... (version ...) for the above project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without my medical care or legal rights being affected.
3. I consent to the interview being audio-taped.
4. I consent to information and quotations from the transcript of the interview being published in the final report (confidentiality and anonymity will be maintained and it will not be possible to identify you from the publication).
5. I agree to take part in the above project.

\_\_\_\_\_  
Name of Participant Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of person  
taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

I do/don't\* want to be sent a copy of the report on this study

\*(delete as appropriate)

When completed: 1 copy for participant, 1 copy (original) for researcher.

## **Ethnicity, Comorbidity and Treatment Service Use**

This is not a structured interview schedule, but a semi-structured topic guide for prospective interviews with people who made contact with South London and Maudsley services for mental health (and substance use) problems between 1997 and 2000. It is unlikely that all interviews will cover all topics. The order, in which topics are covered will in part, be lead by the participants themselves. Questions / topics which are highlighted in bold are likely to come into all accounts: questions / topics not in bold are optional prompts.

### **Introduction:**

Thank you for agreeing to take part in this research (Go through information sheet and consent form. Establish consent for tape recording).

I would like to talk to you about some of your experiences over the last 10 years. I would also like to ask you about your experiences of mental health (and substance treatment) services and find out in your opinion what role they play (if any) in helping you with the things you have been experiencing over the last 10 years.

### **Defining ethnicity:**

- **1. How would you define your ethnicity or your ethnic group?**

#### **POSSIBLE PROBES:**

- Get details of where they were born
- Get details of where their parents were born
- Briefly explore family relationships.

### **Experiences of mental illness::**

- **2. The first thing I want to ask you about is how it was you came into contact with the Mental Health Services for the very first time in?**

#### **POSSIBLE PROBES:**

- Start with the events leading up to their first contact with services.
- Get details of what happened just prior to admission including how the person felt about each event they discuss.

- **3. 'Did you experienced any problems or difficulties in your life around that time?'**

#### **POSSIBLE PROBES:**

- Gage information about any problems they had been experiencing before that event (either social, physical or mental)
- Ask participant if they had confided in friends or family about these difficulties.

- **4. Whose idea was it to go to [name of hospital]? Did any friends or family go with you?**

#### **POSSIBLE PROBES:**

- Ask if any friends or family were involved in the decision to seek help or in the admission itself.

- If they haven't already covered this, ask them to give specific details of the admission (i.e. who assessed them; how long they were in hospital for)
  - Find out if the CJS was involved and how they felt about that.
- **5. Did you think you needed to go to hospital at that time?**  
**POSSIBLE PROBES:**
- Find out if the patient felt they needed treatment for the problems they were experiencing.
  - Were they prescribed medication and did they take it (if not why not)?
- **6. Had you ever experienced any of these things (use patients own words) in your life before going into hospital?**  
**POSSIBLE PROBES:**
- Find out if they had experienced any of the things described before the time they made contact with mental health service for the first time?
- **7. Have you had any of these experiences since that time?**  
**POSSIBLE PROBES:**
- Get detail about any similar experiences they have had since their first contact with mental health services (e.g. when did they start, how long did they last etc)
  - Did they make contact with services for these experiences, and what was the outcome of this (if not why not)?
  - Find out if they ever had contact with the CJS when they were having these experiences.
- **8. How do you feel when you experience these things, and what do you think is the reason for these experiences?**  
**POSSIBLE PROBES:**
- Find out whether they feel these experiences were because of mental illness
  - Do their family and friends believe their experiences were due to mental illness
- **9. Before you had these experiences what did you know or think about mental illness**  
**POSSIBLE PROBES:**
- Find out what they think mental illness is.
  - What did their family/friends know about mental illness before they made contact with services (e.g. other family members with mental illness, contact with people with mental illness)

Experiences of substance use:

- **10. When we interviewed you last you told our researchers that you (used to) use [name(s) of substance]. When did you first start using [name (s) of substance]?**  
**POSSIBLE PROBES:**

- Find out if when they first started using substances and the reasons for that
- Find out how much they were using, whether they still use substances and how much they currently use
- Where they used, in what situations (alone or with friends).

○ **11. Have there ever been points in your life when you've used less often or more often than your normal amount?**

**POSSIBLE PROBES:**

- Gauge whether the patient has had periods of substance abuse, dependence or abstinence (i.e when their use became more than recreational)
- Try to elicit reasons for the possible change in usage of their substance(s) of choice and whether the situations they used in changed as well
- Find out whether they felt at any point in their life that their substance use was a problem for them or other people (friends/family) and was change in frequency/severity of substance use related to this?

○ **12. Have you ever experienced any health problems in relation to your substance use**

**POSSIBLE PROBES:**

- Ask if they have ever experienced any health problems (this can include mental health problems e.g. depression, as well as physical health problem e.g. infections from needles, injuries while intoxicated) which they or others have attributed to substance use
- How did they feel about these problems and did they speak to anyone or do anything to help stop or alleviate these problems

○ **13. Did you ever want to stop your substance use or did you ever seek help for your substance use?**

**POSSIBLE PROBES:**

- Find out if they have ever considered or actually sought help (e.g. GP, mental health or substance service, or other services or agencies) for their substance use
- What were the reasons for this (e.g. to stop/reduce substance use, manage other problems associated with substance use)
- Who did they contact and when did they contact them
- If they never considered or actually sought help why was that?

○ **14. Did you ever have any contact with the police because of drug use?**

**POSSIBLE PROBES:**

- Find out if they have ever had contact with the CJS while taking/dealing drugs either while alone or in a group

**ASK ONLY IF PATIENT CONSIDERED OR ACTUALLY SOUGHT HELP FOR SUBSTANCE USE**

○ **15. What was the outcome of considering/seeking help for your substance use?**

**POSSIBLE PROBES:**

- Ask whether they got a referral / presented to substance abuse treatment services
- If they only considered seeking help why didn't they?
- Get details about any period of treatment they received
- If nothing came of seeking help find out why?

- Have they ever tried or been asked (by friends, family or health professionals) to seek help (again) since that first time they considered /sought help?
- If they haven't already covered this, gauge whether mental health services facilitated them seeking help for substance use (e.g. referral while in hospital or with a community team or detoxification)

○ **16. Did you ever speak to family members/friends about your substance use**  
**POSSIBLE PROBES:**

- Find out whether they have confided in family and/or friends and whether they found this helpful
- Find out what their family thought of (their) drug taking. Use this as an opportunity to get details of family structure, their upbringing and cultural beliefs.
- Ask whether their substance use has caused any problems in their relationships with family or friends
- Were/are any family members or friends involved in helping them monitor their substance use (e.g. contact with treatment services or helping them directly)

○ **17. Have you ever felt your substance use was related to any of the things you have experienced (use patients own words) in the past?**

**POSSIBLE PROBES:**

- Ask if they feel that some of their experiences were a consequence of, made worse or better by their substance use?
- Gauge information about substance use patterns whilst they were having these experiences and the reasons for that.

*Experiences and perceptions of mental health and substance abuse treatment services:*

○ **18. How would you describe your experience of mental health services**

**POSSIBLE PROBES:**

- Find out how they felt they were treated by mental health professionals
- Ask if they were able to see friends and family while in hospital
- If they received treatment in the community ask whether they find/found their care co-ordinator helpful
- What did they expect from mental health services
- If they haven't covered this already, ask if the mental health professionals help them with their substance use
- Did they experience any unfair treatment and why do they think they were treated that way.

○ **19. Do you think being in hospital or being in contact with mental health services was/is useful for you**

**POSSIBLE PROBES:**

- If not previously discussed, gauge whether they feel mental health services have helped them with some of their experiences and/or if they are useful for people with those type of experiences at all
- Ask if the patient thinks that some other intervention or form of help would be more useful for them when they have these experiences.

- **20. How would you describe your experience of substance abuse treatment services**

**POSSIBLE PROBES:**

- Find out how they felt they were treated by substance abuse treatment professionals
- If they were in a detox unit were friends and family able to visit?
- If they have received treatment in the community ask whether they find/found their care co-ordinator helpful
- What did they expect from services
- If they haven't covered this already, ask if the substance abuse treatment professionals help them with any of the experiences they have described earlier (use patients own words)
- Did they experience any unfair treatment and why do they think they were treated that way.

- **21. Have you ever sought help from other types of people/services/agencies for problems with substance use or and of the experiences you've described (e.g. church, community services or natural remedies)?**

**POSSIBLE PROBES:**

- Gauge whether patient has contacted any community or spiritual groups/services
- How did you find out about [name of support]? When did you contact them
- Ask if they found this useful

Current activities and future plans:

- **22. How do you spend your days now? Has that changed since you first were in hospital?**

**POSSIBLE PROBES:**

- Ask if they are working / studying presently?
- Do they see their friends and family more or less than they use to?
- Have they had to change their lifestyle because of their drug use or the experiences they have described?
- Do they have any plans for the future?

## **APPENDIX 2: SEARCH TERMS FOR SYSTEMATIC REVIEW (CHAPTER 3)**

### **1. Drug use terms combined with 'OR'**

Drug addiction, drug abuse, drug dependence, drug misuse, alcoholism, alcohol abuse, alcohol dependence, alcohol misuse, substance abuse, substance abuse, substance dependence, substance misuse, substance treatment, drug treatment, alcohol treatment, comorbid\*, dual diagnosis

### **2. Psychotic disorder search terms combined with 'OR'**

Schizo\*, psychosis, psychoses, psychotic, acute psychosis, depressive psychosis, manic depressive psychosis, paranoid psychosis, alcohol psychosis, manic psychosis, or affective psychosis, bipolar disorder

### **3. Ethnicity terms combined with 'OR'**

Ethnic differences, ethnic and racial groups, minority, racial aspects, ethnic group, ethnic\*, African Caribbean, African American, Black Caribbean, Asian, Asian American, British Asian, Chinese, Indian, Indian American, Pakistan\*, racial\*, race,

Search items 1, 2 and 3 were combined with 'AND'



## APPENDIX 3: COMPARISON OF CONDITIONAL MEANS AND VARIANCES

### Frequency of relapse:

#### *Drug use*

##### Report<sup>a</sup>

LCS 2.6 number of psychotic episodes

comorbid drug use 3 levels	Mean	N	Variance
No drug use	1.6282	78	2.315
Drug use	1.6327	49	3.404
Drug use disorder	1.7500	36	5.850
Total	1.6564	163	3.375

a. 3 eth grps = WBCBA

#### *Alcohol use*

##### Report<sup>a</sup>

LCS 2.6 number of psychotic episodes

comorbid alcohol use 3 levels	Mean	N	Variance
No alcohol use	2.2500	32	5.290
Alcohol use	1.4771	109	2.770
Alcohol use disorder	1.6957	23	3.858
Total	1.6585	164	3.453

a. 3 eth grps = WBCBA

## Frequency of hospital admission:

### ***Drug use***

#### **Report<sup>a</sup>**

LCS 3.1a total number of hospital admissions at follow-up (t3)

comorbid drug use 3 levels	Mean	N	Variance
No drug use	3.1667	126	11.708
Drug use	2.9875	80	8.772
Drug use disorder	4.3226	62	12.878
Total	3.3806	268	11.293

a. 3 eth grps = WBCBA

### ***Alcohol use***

#### **Report<sup>a</sup>**

LCS 3.1a total number of hospital admissions at follow-up (t3)

comorbid alcohol use 3 levels	Mean	N	Variance
No alcohol use	4.5000	56	23.782
Alcohol use	3.0060	168	7.635
Alcohol use disorder	3.4444	45	10.162
Total	3.3903	269	11.657

a. 3 eth grps = WBCBA

## **APPENDIX 4: CODING FRAMEWORKS FOR PHASE TWO QUALITATIVE STUDY**

### **Coder 1 (respondent QS6 only)**

The benefits of hospitalisation

- change in thinking 'knowing not set fires'
- change in and mood

Living context theme

- relates to risk factors (low education, homeless, ethnicity)

Change in drug use theme

- moves from immature 'I can stop whenever to', 'I see there is a need'
- support for quitting

Is drug use separate from mental health?

Prior knowledge of mental illness

Recognising symptoms

- can go in 'recovery' as well as 'experience of illness'

Coping

### **Coder 2**

Psychosis as illness

- Unwell
- Suffering from illness
- 'Had to be sectioned'
- Personal vs. professional symptom description

Symptoms

- External vs. internal origin – 'it was happening to me'
- Description of symptoms as psychosis, mentally ill? Proper psychosis?
- Attribution of cause – external vs. internal

Significant life events

- Unsettled – housing, job, loss, moving

## Agency vs. passivity

### Drug use

- Drug use at time of treatment
- Description of drug use – why use, perceived dependence
- Drugs as normality
- Effects of drug use on self (mental/physical/practical)
- Perceived link to episode/MH
- Current vs. historic views drug use
- Drug use during hospitalisation
- Attention to drug use as part of treatment
- Drug cessation vs. maintenance
- Coping and drug use

### Hospitalisation

- Involvement vs. being done to – passivity vs. agency, contradictions and consistencies
- Perceived reasons for admittance
- Frustration
- Hindsight vs. historic views
- Impact of treatment vs. impact of hospitalisation
- Staff as friends/allies/enemies
- Dissociation from other patients – patients as 'other', special
- Playing the game, acting out
- Inside vs. outside
- Leaving/re-entering community
- Post-discharge care and continuity

### Treatment

- Credibility of staff
- Suspicion
- Doctors/psychiatrists as authority – deferential, external locus
- Willing treatment vs. being sectioned
- Perceived need for treatment
- Awareness of consequences

### Medication

- Adherence
- Drug use (recreational) vs. medication
- Specific vs. vague knowledge (knew exact drug and dosage but vague about diagnosis)
- Efficacy

### Support

- Support from family/friends – prior to episode/involvement with treatment/accessing treatment/post-discharge
- Support from medical staff – psychiatrist vs. nurses
- Church/religion
- Local authority/council

### Views about the self

- Identity

- Self esteem/mastery
- Self-centredness
- Ambition/hope
- Current circumstance/mind set

#### Trajectories

- Events leading up to hospitalisation, impact of drug use and hospitalisation on trajectory, post discharge life, future

### **Coder 3**

#### Defining the experiences

- Terms (psychiatric vs. lay)
- definitions / conceptualisations (physical vs. behavioural)
  - acting out (on purpose as opposed to not being able to help the way you behave)
- emotional / psychological
  - personality change
  - mood change
- symptoms

#### Personality

- Part of the persons pre-existing personality
- Illness
- Anger

#### Causes of the experiences

- located in wider society (responsibility with other)
  - economic
  - institutional
- located in immediate social setting (responsibility with other)
  - family
  - childhood experience
  - financial problems / unemployed
  - interpersonal problems at work
- located in individual (responsibility with self)
  - biological
  - drug abuse
  - psychosocial (stress, relationship breakdown)

#### Definition of self

- ethnicity
- normality
- identification

#### Drug taking

- positive experience
- negative experience
- related to my illness / not related to my illness

## Treatment

- usefulness: needed / not needed (could do table on this)
- positive experience / negative experience (could do table on this)
- what: what they got / what they would have wanted
- definition (what was treatment defined as i.e. the provider)
  - treatment services
  - family support (recognising the person is ill, taking them to the hospital, having someone to talk to / care for you)
- responsibility
  - active / passive participation

## Treatment and recovery

- What (what type of treatment is useful)
  - Medical (medication)
  - Physical (Have a rest, Detox from drugs)
  - Psychological / Emotional (Emotional support / Talking)
  - Practical / social (Getting back routine, Getting job)
- Where (where should it be provided)
  - Hospital
  - Community
  - Home
- Who (who should provide treatment)
  - The individual (self)
  - Local community / institution
    - Mental health services
    - Drug treatment services
    - Criminal justice service
    - Family
    - Wider Society
- How (how is treatment provided and recovery made)
  - goal
    - psychological
    - be myself again
    - being a different person (better)
    - social / economic
    - rest Power struggles
  - Causes of experiences
  - Forcibly made to detox
- Why (Why is treatment needed; for purpose does it function; who benefits)
  - Social (Better my relationships)
  - Psychological (Be a better person)
  - Economic (Get a job)

## Final Coding Framework

MAXQDA

29/07/2013

### Code System [3589]

- spare codes [0]
  - In-Vivo Codes [1]
    - we just got on with it [1]
    - key words [62]
  - Changes in their life [4]
  - Postive experiences of drug taking [3]
  - Other (1) [0]
    - family worry about drug taking [1]
    - dishonesty about drug taking [1]
  - Other [0]
    - expectations of illness [1]
    - chicken and the egg [1]
  - Account devices [6]
    - How [0]
      - intellectualising the expereinces [30]
      - apportioning responsibility [12]
      - justifications [35]
      - excuses [34]
      - Association: Film analogies and film metaphors [7]
    - What [0]
      - Feeling and Doing [0]
        - How I feel/felt [28]
        - What happended / what I did [39]
    - When [0]
      - Hindsight [0]
        - Then and now [7]
          - I didn't agree then but I do now / I know now I needed treatmen [21]
          - I didn't know at the time anything was wrong/I know now I need [10]
      - Then [0]
        - Recall around experiences - remembering and not remembering [5]
          - Device used as prompt for interviewer to remember [3]
          - Device not clearly used or not used [5]
          - I remember [17]
          - I don't really remember [56]
    - Recall and Retrospection [0]
  - Me, Myself and I [0]
    - my strength [16]
    - Vulnerability [28]
    - i wasn't understood [22]
    - There wasn't anything wrong with me [16]
    - It wasn't me [23]
    - reason enough [19]
  - Drug and mental health relationship [0]
    - C3 [0]
      - drug use is not related to my mental health treatment [15]
      - drug use related to my mental health [41]
    - C2 [0]
      - I have/had a mental illness [23]
      - I didn't have/don't have a mental illness [26]
    - C1 [0]
      - I do have a problem with drug use/addiction [34]
      - I don't have a problem with drug use/addiction [15]
    - not understandin about drugs or consequences [12]
    - mh treatment related to drug treatment [5]
    - mh treatment not related to drug treatment [3]

Terminology, Signs and Timelines [10]  
 what are people with mental health problems like [15]  
 different types of illness/different types of treatment [17]  
 Substance use after initial episode [0]  
 stopped substance use [25]  
 continued substance use [16]  
 Changes to substance use [7]  
 Timelines [24]  
 Terms [0]  
 psychotic depression [1]  
 emotionally ill [1]  
 socially withdrawn [1]  
 ill / illness [22]  
 nutty [1]  
 unstable [1]  
 crazy [16]  
 mood disorder [1]  
 bipolar [2]  
 loopy [1]  
 mental health issues [2]  
 nutter [1]  
 delusional [1]  
 lunatics [1]  
 psychosis [4]  
 bubbly [1]  
 paranoid schizophrenia [5]  
 paranoia/paranoid [32]  
 depressed [21]  
 mad [8]  
 vexed [3]  
 affecting my head [5]  
 Low [3]  
 funny [2]  
 Mental [11]  
 bonkers [3]  
 I went manic. [6]  
 high [5]  
 bit of a struggle [2]  
 rushed [4]  
 breakdown [9]  
 mental illness [7]  
 Constructions of race, ethnicity and culture [40]  
 Terms [4]  
 Physical [10]  
 Geographical [18]  
 Spiritual [1]  
 Views about the self and other [0]  
 I am the same as other patients [14]  
 I am different from other patients [41]  
 Support [0]  
 owe my life [5]  
 Who [1]  
 society/system [16]  
 church / spiritual / alternative [11]  
 Me [46]  
 Friends: other patients becoming friends [6]



- Expectations of treatment [26]
  - Credibility of staff [13]
    - Staff being respectful [5]
    - Not having a good relationship with staff [10]
    - being intelligent [9]
    - Staff being professional [9]
    - not just the job [12]
    - more than just medication [22]
    - Consistency/ Post treatment and continuity of care [12]
    - consistency of staff [6]
    - trust in treatment [27]
    - Psychiatrists as authority [4]
  - responsibility for treatment [20]
  - GP [44]
  - CJS [7]
  - Drug treatment service [5]
  - Mental Health Services [27]
    - supported community placements [4]
  - Family as a support network [41]
    - recognising their ill/monitoring [30]
    - Power relationships during recovery between fam/fr and patients [19]
    - views of involvement (positive) [28]
    - views of involvement (negative) [27]
      - I didn't or need their help [10]
    - pre-existing family structure or dynamic [41]
- What [0]
  - Normality [13]
    - need to be myself/normal again [15]
    - doing normal things [19]
  - Psychological / Emotional [4]
    - therapy [13]
    - talking about problems as treatment/coping mech [33]
    - emotional support [17]
    - Change in thinking process [27]
    - noticing change in behaviour [4]
    - Dealing with the causes of experiences [23]
  - Practical / Social [1]
    - economic support [9]
    - not feeling alone [7]
    - practical support [21]
    - taking the pressure off (economic) [5]
  - Medical [4]
    - taking medication [30]
    - compliance [11]
- Mastery and Involvement [0]
  - experiences of mental health [0]
    - no experiences of mental health [10]
    - experience or family experience of mental health system [11]
  - family history of mental illness [0]
    - no family history [14]
    - family history [7]
  - Active and passive involvement in treatment and recovery [0]
    - denial [9]
      - avoidance [4]
    - initiating interventions for yourself [22]
    - initiating treatment then not attending [4]

- i just got on with it / resigned myself to treatment [16]
  - because the professionals said so [6]
- Challenging [15]
  - absentness in treatment [11]
- Control and power in the treatment process [9]
  - control over and power in treatment received [45]
  - control over medication received [30]
- i am my intervention [44]
- Understanding experiences [45]
  - staff giving explanation of experiences [27]
  - information about drug taking [13]
  - Insight/ill vs not ill and insight into effects of drug taking [64]
- Negative experiences [0]
  - being labelled [14]
    - hidings things and embarrassment [10]
  - cjs system not helpful [9]
  - hating medication [18]
  - fear of my experiences [19]
  - Negative experiences of drug taking [37]
  - relationships (and changes) with familiy [31]
  - Expolitation/unfair treatment [29]
    - punishment [4]
  - medication side effects [16]
- Hospitalisation [0]
  - behaviour yardstick internal and external (social norms) [16]
- Inside vs. Outside [34]
  - Prison parallel [34]
    - not doing drugs in hospital [6]
    - behave how they expect/ get what you want [9]
    - i could smoke on the ward because i could get it [9]
- Usefulness / Role (1) [6]
  - think about things [1]
  - stop using substances [1]
  - acting out [2]
  - support [7]
  - None [8]
  - Rest [6]
  - Not being in prison [7]
  - Safety [4]
- Frustration and Fear [20]
  - Force [17]
- Constructing addiction [10]
  - frequency and quantity [5]
  - cannabis is not an addictive drug [2]
- Physical [5]
- Social [1]
  - Normal function so drugs not problematic [8]
- Psychological [6]
  - Control in drug taking/willpower [7]
  - It helped me cope [14]
- Cessation vs. Continuation of drug use since first episode [7]
  - Psychological [12]
    - Psychological (personality) [6]
    - Choice and willpower [29]
- Economic/legal [7]
  - work [1]

- Legal sanctions [6]
- Not enough money or having extra money, gaining money [14]
- Social [0]
  - drug use and the usic scene [25]
  - friends / social relationships [41]
- Substance use related to physical/mental health [33]
  - self medication [20]
  - making me paranoid [15]
  - cannabis use not problematic [18]
  - becasue the health professionals told me to [6]
- How drug use is discontinued [18]
- Internal and External (LOC and Behaviour) [5]
  - Internal [18]
  - External [68]
- Coping [3]
  - dependency on services [10]
  - dependency of medication [1]
  - pre-exisiting family structure or dymanic [9]
  - talking about problems as treatment/coping mech [9]
  - substances helped me cope [32]
    - self harm [2]
    - sleep [1]
    - structure [3]
    - spiritual help [1]
- Feelings, Behaviours and Thoughts [0]
  - Feelings [0]
    - Emotional feelings [46]
    - Physical feelings [22]
  - Behaviour [24]
    - suicide experiences [11]
    - criminal behaviour [11]
  - Thoughts [28]
    - Paranoia [27]
  - management of illness/symptoms [23]
- Causes of experiences [3]
  - Causes of experiences: Spiritual [6]
  - The positive side of illness/experiences [15]
  - Not just one reason [16]
  - Causes of experiences: emotional / psychological [5]
    - Life event/stress [49]
    - Personality [20]
  - Causes of experiences: organic / biological / chemical [13]
    - not taking medication [4]
    - drug use [34]
- Reasons for drug use over lifecourse [0]
  - Causes of initiating drug taking: Psycho-social [12]
    - psychological [0]
    - depression/grief [2]
    - stress [1]
    - causes of initiating drug taking: Relationships [5]
  - Causes of initiating drug taking: Circumstantial [35]
  - Causes of initiating drug taking: Physical (substitution) [7]
- GREEN [0]
- Sets [0]
  - Set 1 [0]